Seeing & *Saying*: Visual imaginings for disease causing genetic mutations

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Abstract

Using practice based research methodologies this thesis, *Seeing & Saying: Visual imaginings for disease causing genetic mutations,* explores the visual and linguistic narratives that emerge from the explanation of complex genetic diagnosis. The research, funded by the Arts & Humanities Research Council (AHRC), is being carried out in collaboration with the European Network of Excellence for rare inherited neuromuscular diseases (TREAT-NMD), coordinated by the Institute of Genetic Medicine at Newcastle University. TREAT-NMD is an international initiative funded by the European Commission linking leading clinicians, scientists, industrial partners and patient organisations in eleven countries. Located in this complex field of study, between the disciplines of art and science, this research project explores the contextual framework of the social and cultural histories that influence and give agency to the visual and text based metaphors that are used to depict and diagnose the specific genetic disease of Duchenne muscular dystrophy (DMD). The use of linguistic metaphors and visual imagery is commonplace when interpreting the how, what, why and where of DNA and it is these types of metaphorical communications that will form the basis of this investigation. This thesis interrogates and extends research methods and processes that develop from studio practice, scientific laboratories and text-based analysis thus creating a synergy between the scientific laboratory and the artist's studio. This written thesis and the artworks produced are therefore both the narrative and the output of this collaborative relationship that represents a synthesis of the methodologies of art and science. By examining the communication between the network stakeholders of TREAT-NMD and studying how linguistic, visual and artefactual metaphors impact on the construction of technical explanations within this network, this thesis proposes that we can come closer to answering how we *see* and how we *say* genetic disease.

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NB unless otherwise attributed all images are author's own.

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Completion of this research would not have been possible without the support of my sons Jack and George and my partner Henry, who on top of everything else actually read this thesis…

Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions from the work of others. The research was carried out in collaboration with the TREAT-NMD network.

Any ethical clearance for the research presented in this thesis has been approved.

Approval has been sought and granted by the School Ethics Committee on 13/01/10.

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Signature:

Date:

1 Introduction

> Science is seen as having a special kind of value to which we all owe allegiance. People who want to list the glories of our civilisation are almost sure to list science... among them, along with art. And the special value of science, like that of art, is not to reach only the few who produce it, but also the public which receives it. (Midgley, 1992: p.3)

Using practice based research methodologies this thesis explores the visual and linguistic narratives that emerge through the process of explaining complex genetic diseases and diagnosis. The investigation is located in a diverse and complex field of study that includes, but is not limited to, art and science, biological medical science, genetics, linguistics, medical humanities and arts practice. It has been necessary at times, for the purpose of this investigation, to include references to what are quite clearly much larger theories and debates that cannot be fully explored here as they are not central to this research.

Whilst this work explores the contextual framework of the social and cultural histories that influence and give agency to this collaborative project, this thesis interrogates and extends research methods and processes that develop from studio practice, scientific laboratories and text-based analysis; in this it is a hybrid that nevertheless aims to represents a synthesis. This written thesis and the artworks produced are therefore both the narrative and the output of this collaborative relationship that came into existence at the beginning of the research project between the researcher and the TREAT-NMD network, based at the Institute of Genetic Medicine in Newcastle upon Tyne.

1.1 TREAT-NMD and DNA

TREAT-NMD is an international Network of Excellence addressing the fragmentation currently hindering translational research for cutting edge therapies in rare neuromuscular diseases that was established in 2007. Situated at Newcastle University's Institute of Genetic Medicine the network is coordinated by Professor Volker Straub who is Harold Macmillan Chair of Medicine and a supervisor for this PhD. TREAT-NMD stands for Translational Research in Europe – Assessment and Treatment of Neuromuscular Diseases and is an international initiative funded by the European Commission linking leading clinicians, scientists, industrial partners and patient organisations in eleven countries. The aims of TREAT – NMD are to:

> Provide an infrastructure to ensure that the most promising new therapies reach patients as quickly as possible...the network's focus has been on the development of tools that industry, clinicians and scientists need to bring novel therapeutic approaches through preclinical development and into the clinic, and on establishing best-practice care for neuromuscular patients worldwide. (TREAT-NMD, 2007)

Neuromuscular diseases (NMD) are disorders that affect one of four anatomical structures: the anterior horn cell in the spinal cord, the peripheral nerve, the neuromuscular junction or the muscle cell itself. Many neuromuscular diseases are of genetic origin, which means they are not acquired but caused by sequence variants in the DNA. These genetic neuromuscular diseases are the ones that TREAT-NMD addresses. Inherited NMD form a large group of diseases each of which is individually rare (prevalence < 5/10,000). They are present in all populations and affect both sexes, children and adults. Most NMD result in chronic long term disability posing a significant health care burden for society. Death may result from cardiac and respiratory muscle involvement. Over the past twenty years, molecular genetic advances have allowed the development of specific diagnostic tests for many types of NMD, via the delineation of the underlying gene and protein defects. Knowledge of disease causing genes has begun to allow the elucidation of the molecular pathological

mechanisms underlying NMD, leading to plans for specific gene based therapies or targeted pharmaceutical approaches. These developments, while universally welcomed amongst scientists, clinicians and patient organisations, have exposed the lack of communication between the different stakeholders.

This research investigation will use as its focus Duchenne muscular dystrophy, which is one of the most common and best characterised NMD, affecting approximately 1 in every 3,500 male births worldwide. It is caused by a genetic change (mutation) in a gene called the DMD gene. A fault in this gene stops the body making a protein called dystrophin. This protein is important in muscle fibers, and its absence leads to ongoing damage of muscle cells resulting in progressive muscle weakness. As the DMD gene is on the X chromosome, Duchenne muscular dystrophy generally only affects boys (except in rare cases). Girls have two X chromosomes, so if one of these is unaffected it can usually compensate for the affected one, while boys have one X and one Y chromosome, so if their single copy of the DMD gene on the X chromosome is affected, they have the symptoms of Duchenne muscular dystrophy. Girls with one affected gene and one normal one usually won't show symptoms but are "carriers" of the genetic change and can pass it on to the next generation. A carrier mother has a 50:50 chance of having a son who is affected.

Most affected boys develop the first signs of difficulty in walking at the age of 1 to 3 years. They often walk later than other boys their own age, have enlarged calf muscles and have trouble running, jumping or climbing stairs. They fall easily and may have a tendency to walk on their toes. One of the classic signs of Duchenne muscular dystrophy is what is known as the "Gower’s” maneuver, where the boy has to use his hands and arms to "walk" up his body in order to push himself to an upright position. This is due to weakness in the hips and thigh muscles. Some boys also have learning and or behavioral difficulties.

Figure 1 Gowers' manoeuvre *Gowers WR. (1879)* Pseudo-hypertrophic muscular paralysis: a clinical lecture

Typically, boys with Duchenne muscular dystrophy lose their ability to walk between the ages of ten and fourteen. By their late teens, they lose the strength in their upper bodies, including the ability to move their arms. The disease also affects the heart and breathing muscles, so around this time they also usually need help with breathing at night. Over time, their respiratory systems weaken, and they require constant support. Patients with Duchenne muscular dystrophy do have a shorter life expectancy but advances in management of the condition have increased life span significantly and enabled affected young men to lead much more independent lives than was previously possible. While there is still no cure for Duchenne muscular dystrophy, it is one of the conditions where there is substantial active research and where several potential new therapies are currently being tested in clinical trials. It is also a condition for which experts have established internationally approved care guidelines that can make a big difference to the quality of life and life expectancy of a boy with the disease. (TREAT-NMD, 2007: /dmd/about)

Key writers on Duchenne muscular dystrophy such as Alan Emery[1] have traced historic images in an attempt to identify the earliest acknowledgement of the disease arguing that, '…Duchenne muscular dystrophy, is so distinctive it seems quite possible that it was observed and perhaps even recorded from earliest times' (Emery, 1995: p.9). This early history, in particular the early visual depictions of the disease, are examined more closely later in Chapter 3 of the thesis.

[1] For a full history of the Duchenne muscular dystrophy see Emery AEH. (1995) *The history of a genetic disease : Duchenne muscular dystrophy or Meryon's disease,* London: Royal Society of Medicine Press.

DNA, or deoxyribonucleic acid, which is at the centre of this thesis, is the hereditary material in humans and almost all other organisms. Nearly every cell in a person's body has the same DNA. Most DNA is located in the cell nucleus (where it is called nuclear DNA), but a small amount of DNA can also be found in the mitochondria (where it is called mitochondrial DNA or mtDNA). The information in DNA is stored as a code made up of four chemical bases: adenine (A), guanine (G), cytosine (C), and thymine (T). Human DNA consists of around 3 billion bases, and more than 99 percent of those bases are the same in all people. The order or sequences of these bases determines the information available for building and maintaining an organism, similar to the way in which letters of the alphabet appear in a certain order to form words and sentences.

DNA bases pair up with each other, A with T and C with G, to form units called base pairs. Each base is also attached to a sugar molecule and a phosphate molecule. Together a base, sugar, and phosphate are called a nucleotide. Nucleotides are arranged in two long strands that form a spiral called a double helix. The structure of the double helix is somewhat like a ladder, with the base pairs forming the rungs of the ladder and the sugar and phosphate molecules forming the vertical sidepieces of the ladder.

An important property of DNA is that it can replicate, or make copies of itself. Each strand of DNA in the double helix can serve as a pattern for duplicating the sequence of bases. This is critical when cells divide because each new cell needs to have an exact copy of the DNA present in the old cell. (National Institute of Health, 2012)

1.2 The Researcher in Context

The hybridity of the research project is paralleled to that of the researcher. With a background in two disciplines, that of creative writing and the visual arts, the researcher draws upon visual and linguistic approaches. Indeed previous practice drew on textual elements that were disturbed and/or changed within earlier artworks. It is this 'disturbance' of the physical word or text that is brought to bear in this research project. In particular the research examines the narrative that emerges from creating objects that are inhabited by textual absence and it considers how this is informed by the tracery of memory and remembered knowledge and, perhaps sometimes, an imagined truth.

These creative experiments have used a number of materials conventionally associated with an expanded definition of fine art practice, such as glass, paper, photography etc., but they also include materials used in clinical experimentation such as gels. This research investigation crosses between, and combines, the two disciplines of art and science both through the materials of an arts practice and a scientific laboratory and through the methods and conventions of display that are generally adopted within both of these fields of knowledge. It is into this unstable environment that text and images are introduced, held, changed and finally 'unsettled'. Through practical and reflective exploration, this research aims to get closer to the experience of 'wondering' rather than 'knowing', creating a gap in understanding that then leaves room for the narrative structure of metaphorical 'story-making' and 'imagining' to occur.

1.3 The Research Question

This research project focuses on the key question of how one might use fine art practice, specifically forms of visual representation based in diverse studio methods, to begin to understand the complexities of DNA. This investigation is located in the context of disease causing genetic mutations and in particular the mutation that causes Duchenne muscular dystrophy. A specific objective is to articulate the interplay between *seeing* and *saying* especially as the genetic diseases at the core of the TREAT-NMD research project are both difficult to *say* and to *see* and thus to explore both the linguistic and visual imaginings that are used within this context.

Doctors treating patients with incurable genetic conditions have long been aware that their approach to explaining something as intangible as a genetic diagnosis is very different from the way a patient may conceptualise their own condition. The general public has a different perspective again, and speaking to scientists and researchers reveals yet another way of "understanding" genetics. TREAT-NMD is an international network that brings together all of these stakeholders, yet in spite of the formal links this creates, this type of communication mismatch still persists and can result in frustration and disappointment arising out of thwarted hopes and unrealistic expectations. In an effort to overcome these communication difficulties, both doctors and patients often utilise verbal and visual metaphors. When the verbal expression of biomedical concepts becomes highly visual in this way, scientific language starts to share much common ground with the arts. Exploring and building on this tendency allows the possibility of new and better means of overcoming the communication barriers. The narratives that emerge from the visual to make meaning and linguistic metaphor and analogy all combine and contribute to the 'translation' of difficult concepts. How we 'see' disease is not just the visual interpretation of 'signs' of disease i.e. how the disease physically manifests itself, but how we see and interpret this image is embedded in the visual and linguistic culture of the viewer. Through visualising and physically making interpretations of this kind of

metaphorical communication, this research project develops visual methods and strategies from an arts practice in order to articulate a discourse between the *seeing* and the *saying*.

1.4 Research Strategies

Due to the complex nature of the context for this investigation various research strategies were employed for the exploration and dissemination of the research outcomes. As well as using studio based research methodologies, to immerse the arts practice in the 'science' of the TREAT-NMD network, various exhibitions and events were held during the course of the investigation. These included art exhibitions, which due to the public nature of the events resulted in invitations, a leaflet and press releases (Appendix 1), as well as a radio interview about the project. There was also a panel discussion that took place alongside an art exhibition (Appendix 2), and presentation of the project to patient organisations such as The Jennifer Trust (Appendix 3). Various posters were presented throughout the course of the research both at humanities and purely science based conferences (Appendix 4) and research papers were delivered to research seminar groups across both disciplines. The *Language Lab* website (Wilde, 2009) was developed by myself as a means to engage the TREAT-NMD network with the ongoing research project and has been used throughout the research as a means to show the studio work through the online gallery and to collect the metaphorical language used by the TREAT-NMD network (Appendix 5). The website was featured in the keynote address at the International TREAT-NMD Conference in Geneva, 2011 (Bushby, 2011) and I gave a research paper at the same conference (Wilde, 2011). In this non-traditional art environment, images of the work *Presents as…* [Fig. 25] were projected on a large screen throughout the conference and a postcard was distributed to all of the conference delegates. (Appendix 6)

These various research strategies have been applied as the collaborative nature of this project offers a unique research environment where the artists' studio meets the laboratory. At this interface of science and art, this investigation questions the ways in which visual and literary metaphors are deployed by geneticists at the forefront of gene research.

1.5 Structure of the Thesis

As outlined above this thesis is part of a practice based inquiry that considers the visual imaginings, constructed through the use of 'pictures' and 'words', that are used to communicate disease causing genetic mutations. Through a sustained investigation this thesis has been researched and developed alongside an arts practice that has been immersed in, and therefore responded to, the context of collaboration with the TREAT-NMD network. The following chapter, Chapter 2, *Literature Review*, is a review of the literature and artworks that are located within the field of art and science and in particular the area of genetic research and disease. There is a broad survey of examples of artists whose work is influenced by and/or is questioning of, the biological sciences and genetic research. Chapter 3, *Seeing: The visual imaginings of disease,* discusses historic figures such as Duchenne de Boulogne and Heinrich Curschmann and how the process of photography in the medical environment was used to create portraits of sick and diseased patients who were attending the clinics of these two clinicians. There is also a survey of how medicine in culture has been perceived and visualised over the course of time and with changing technologies. Chapter 4, *Saying: The linguistic imaginings of disease* is a consideration of the use of linguistic strategies that are used to communicate complex scientific and genetic information. In particular the use of analogy and metaphor as a mechanism and how this language has become embedded in medical and popular culture. Chapter 5, *Studio practice as research,* is a reflective narrative of how the arts

practice has been immersed in and responded to this research investigation. The chapter charts the progress of the developing artworks in the studio from initial ideas and experimentation and how the practice interacted with the TREAT-NMD network. Chapter 6, *Research outcomes: The Artworks* brings together the completed artworks and discusses how the works came to completion and the strategies for display that were implemented whilst chapter 7 draws together the strands of this research and assesses the practical applications and strategies that have been used for dissemination and implications of the project. This chapter also provides some suggestions towards future research.

2 Literature Review

2.1 Introduction

This chapter focuses on a review of the key literature and a survey of arts practice as it connects with science, in particular the area of genetic research. The aim is to provide a clear discursive context for examining this subject paying particular attention to the circumstances of the research which has developed through a collaborative project with the TREAT-NMD Neuromuscular Network. Inevitably this is a wide field, but the focus here is on the literature and arts practice that considers metaphor in this context. This chapter will give some examples of how arts practitioners working in this field have approached the subject and also considers both the historical and social implications of what is often referred to as the 'genetic revolution'.

This survey of literature and arts practice aims to contextualise and assess those writers and practitioners who have attempted to communicate across visual and linguistic barriers. Inevitably the literature ranges across these three broad categories, but can be narrowed down to more specific fields with the primary focus being on that of art and science. The TREAT-NMD network is concerned with medical issues and research in the field of neuromuscular diseases and is therefore based within the biological sciences. The general study of metaphor lies within the field of linguistics, however this research project is firmly located in the visual arts as it deploys representational practices originating in fine art to answer the research question. At the interface between art and science, this research project considers the relationships between medicine and culture particularly since the mapping of the human genome began. This specific context provides the general background for this literature search which is concerned with the communication of disease diagnostics through visual and linguistic means. There is a significant body of literature that considers the scientific and social implications of this discovery and consequent mapping of the genome (see for example Dawkins, 1989; Kay, 2000; Keller,

2002; Pollack, 1994; Roof, 2007). The relationship between art and science is well documented and there has been a steady increase in 'Sci-Art' and art science collaboration within the visual arts. Comprehensive commentaries of such projects have been documented from the perspectives of both the arts and the social sciences. (see for example Ede, 2000; Ede, 2005; Anker and Nelkin, 2004; Kemp and Wallace, 2000; Wilson, 2010). The use of linguistic metaphor and analogy is commonplace when communicating complex data and ideas across disciplines and within cultural and social frameworks. For the purposes of this research the study of conceptual metaphor, within the relatively new field of cognitive linguistics, namely that of Lakoff and Johnson, has been used as a primary source for expediency.

2.1 Historical Context

This literature review examines contemporary writing that deals with the relationship between art and science since the discovery of DNA in 1953 and more recently the mapping of the human genome which was completed in 2000. The ideas emerging from this field of study are summed up by Dorothy Nelkin as those of *awe* and *fear* at the seemingly limitless potential of all that the human genome can tell us (Anker and Nelkin, 2004). The methods, by which genetics and genetic research are perceived i.e. the public perception, are steered by how this relatively new and complex science is communicated. For whilst the Human Genome Project itself gave us *'the world's greatest history book'*, a quote attributed to Eric Lander[2] of Massachusetts Institute of Technology (MIT), it has also allowed for the development of knowledge that will change, through medical intervention, the future of this 'genetic book'. Our ability to interpret and understand this hitherto invisible landscape of literally what we are made of is a seemingly on going

[2] Eric Lander is a Professor of Biology and was one of the leading researchers on the publicly funded Human Genome Project (HGP). The public draft of the human genome was published in 2001 in the journal *Nature*.

challenge. Not only do we need to be able to 'read' this information we also want to understand and translate it into action – we want to be able to use it, to change and improve 'ourselves' and of course to 'fix' the 'bits' that are broken:

> An explanation of the mechanism of heredity involves novel actions of novel entities...The story involves unfamiliar objects which do unfamiliar things in an inaccessible world. (Ogborn, 1996: p.10)

This 'unfamiliar' thing that is intrinsic to the human identity has moved the world of medicine beyond just the doctor patient relationship and has become central to interpretations of the very nature of the life and death of the human species. There are a number of key writers who consider the relationship between art and science in their work including the art historian Martin Kemp and the social scientist Dorothy Nelkin. Writing for *Nature* magazine, art historian Martin Kemp asked 'so can art be science and science be art?' (Kemp, 2005: p.308). Siân Ede, Arts Director of the Gulbenkian Foundation, who has pioneered projects bringing artists and scientists together asked in her influential book *Art and Science*, 'Is science the new art?' and suggested that the 'public is better informed about contemporary science than it is about contemporary art' (Ede, 2005: p.1).

However while science and art 'share a cultural context', these two disciplines also represent quite different ways of 'knowing the world' (Anker and Nelkin, 2004). As A.S. Byatt argues, the most striking distinctions are that they appear to occupy ' two separate churches with entirely separate doctrines' (Ede, 2000: p.16). Whilst the disciplines 'share' they are also 'separate'. These 'distinctions' are borne out by the dictionary definition of what is art and what is science, art is defined as:

> …the expression or application of human creative skill and imagination, typically in a visual form such as painting or sculpture, producing works to be appreciated primarily for their beauty or emotional power… (Chambers, 1998)
>
> Science is defined as:
>
> The intellectual and practical activity encompassing the systematic study of the structure and behaviour of the physical and natural world through observation and experiment. (Chambers, 1998)

Given these definitions, one can see the basic difference at a literal level, one discipline is based in facts, learned through 'systematic' study and 'experiment' and the other is the 'application' of 'creative skill' and 'imagination'. Meanwhile, finding the similar in the dissimilar, expressing one thing as another is rooted in the fundamental theory of metaphor put forward by Aristotle in The Poetics. 'To see metaphorically,' according to Aristotle, 'is to create meaning, through synthesis, by discovering what is similar in dissimilar things' (Aristotle and Lucas, 1968). Whilst this is a language based theory, the 'meaning making' that occurs in this context often creates a visual metaphor that represents something other than itself.

For one discipline to become or replace the other, as suggested in the questions posed by Ede and Kemp, each discipline would adopt the 'applications' and 'activities' of the other. It is clear that some artists work in a 'systematic' and 'practical' way, something that is inherent in arts practice itself, and conversely for the scientist to use 'creative skill' and 'imagination' during the course of scientific research. Ede refers to what she terms as a 'rift' that 'derives from the radical differences in two epistemological traditions concerned with the nature of knowledge itself'. (Ede, 2005: p.5) And Martin Kemp warns that 'we serve any inquiry into art and science badly if our criterion is superficially the influence of science on art, or the influence of art on science' (Kemp, 2005: p.308). Kemp points out that whilst important to acknowledge the debates, to 'generalise' about this relationship is 'not so much hazardous as impossible' (Kemp, 2005: p.309). For neither art nor science are 'homogenous categories'. Whilst 'generalisation' in itself may have its failings there does seem to be a 'general' consensus about what are some of the commonalities between the Artist and the Scientist. These are, 'the quest for knowledge, the quest for truth and the quest for beauty…' (Kemp, 2005: p.308). Alternately, Byatt suggests that 'the artistic culture', (as Sian Ede demonstrates) 'differentiates itself from the scientific culture…often by characterising itself as the subversive, the destabilising, and the

contrary' (Ede, 2000: p.7). On the one hand the 'quest' is driven by the same motivating factors, on the other there is a need to differentiate, possibly to 'destabilise'. It is questionable if the majority of scientists, or indeed all artists, would agree with Kemps suggestion that they are searching for beauty. That is not to say that 'beauty' in its broadest sense is not present in the sciences and that not all artists in this area would describe their work as necessarily 'contrary' or 'destabilising'. Whatever conclusion these debates may bring the literature in this area consistently draws comparisons and discusses 'influence' and 'difference' in order to find a way through the debate. What is evident is that both disciplines are about questioning and finding out; Kemps 'quest for knowledge' (2005).

2.2 A Revolution

In the last half century technology has advanced so rapidly that the very nature of how we engage with the world around us has altered. Dorothy Nelkin has argued that the relationship is evolving; the 'old' model assumed that 'science' representing progress and truth was 'the ideal way of investigating and classifying the world'. The changes are that today the relationship is 'less idealistic', 'less optimistic'; therefore there exists 'a changing narrative between art and science' (Anker and Nelkin, 2004). In contrast others have argued that the growing general interest in advancing technologies and the accessibility of information has nurtured the relationship and that the 'narrative change' has been a positive one (see for example Saunders *et al*., 2009; O'Riordan, 2010; Wilson, 2010). Evidence of this can be seen in the growth of collaborative art and science projects, often funded by medical/scientific organisations such as the Wellcome Trust,[3] the Sanger

[3] The Wellcome Trust was established in 1936 as an independent charity funding research to improve human and animal health. In addition to funding biomedical research it supports the public understanding of science.

Institute[4] and the Gulbenkian Foundation;[5] that have afforded more opportunity for a cooperative and collaborative approach to artistic interpretations of the world of the laboratory.

The changing narrative identified by Nelkin is borne out of the 'Genetic Revolution', a term used to encompass the major scientific advances in genetic research over the last 60 years. If, as A.S. Byatt argues, 'we think out ourselves and our place in the world in terms of what we know of astrophysics, or genetic research or microbiology etc.,' then the speed of the change of 'what we know' about genetics has been so rapid that it has changed fundamentally how 'we think ourselves out'. (Ede, 2000: p.7) It is this way of 'thinking ourselves' that is at the heart of the concerns voiced by social and cultural scientists such as Nelkin. It is this question of identity and how we are made that is often explored by the visual arts. In the context of this research, the key question is how the 'new knowledge' of genetics, and specifically the knowledge about disease causing gene mutations, is communicated visually?

2.3 The Gaze: The Physical Body

The relationship between the arts and science in the context of the 'genetic revolution' arguably continues a long tradition regarding how the artist interprets and makes sense of the wider world and the physical human body. Just as historically the drawings of Vesalius used 'visual devices to convince the reader of the physical truth of his observations' (Kemp, 2000: p.23) so now, in the twenty first century, it is the molecule and

[4] The Wellcome Trust Sanger Institute (previously known as The Sanger Centre, established in 1992) is a non-profit, British genomics and genetics research institute, primarily funded by the Wellcome Trust.

[5] The Calouste Gulbenkian Foundation is a charitable foundation established in Portugal in 1956 with cultural, educational, social and scientific interests. The purpose of the UK Branch in London is to enrich and connect the experiences of individuals, families and communities, with a special interest in supporting those who are most disadvantaged.

not the physical body that dominates. The challenge for the 'genetic' artist is to interpret the molecular level of the human without the physical truth of the observed body. Whilst Galen to Vesalius to Da Vinci aimed to see how the body worked, using 'the principles of deducing function rigorously from an observed form' (Kemp, 2000: p.23), genetic information is not visible in the same way. For artists exploring the world of genetics, the physical body is not necessarily present in the traditional corporeal way but rather through a more obscure method of visualisation. Thus one could argue that the models that were used to illustrate the body and its functions have reached a limit when it comes to the illustration of complex genetics. In an important article entitled the *Influence of Genetics on Contemporary Art*, Anker and Nelkin argue that:

> By the 1950's scientists were reconceptualising the body, transforming it, in effect, from a morphological structure, to a molecular organisation, from organism to text, from flesh and blood to information. (Nelkin and Anker, 2002: p.968)

This 'reduction' of the physical form of the human is something that permeates many 'genetic' artworks. As Ede suggest 'we so sensuously inhabit our own bodies that it is hard to see them as systems of knowledge even in the purified arena of the laboratory…' (Ede, 2005: p.133). This 'reconceptualising' of the human body into some other form of visualisation, given the intrinsic nature of the flesh and bone to the self, creates an arena where one thing that is known (the physical body) can be 'seen', and 'visualised' in a way that is not 'like' the commonly perceived view of the physical form.

The historical artistic representation of the body has explored the physical form from the outside to the inside. Anatomically detailed drawings, such as those by Vesalius and Da Vinci whilst aesthetically pleasing were also extremely accurate. Artists such as Francis Bacon, Lucian Freud have portrayed the human form as 'fatty and sinewy as meat' (Ede, 2005: p.134). Controversial works such as Gunther von Hagen's Body Worlds '...reflects a new interest in body as machine' the human flesh is 'clean and odourless' and 'delicatessen cured' (Ede, 2005: p.136). Whilst contemporary artist Christine Borland

‘resurrected’ the plaster cast of a partially flayed corpse in her work *Cast from Nature (2011).* Here the work explores the historic cast and resurrects not simply the physicality of the sculpture, but also the performative aspects of display and in this case references the dissection theatre.

The physical representation of the body in art, history and culture is well documented by those such as McGrath (McGrath, 2002) who examines exterior and interior images of the female body using examples from medical archives, Stephens (Stephens, 2011) who traces the history of the physical body in exhibition and Ruth Richardson who charts the representation of the physical body in society, with an historic account of 19th century attitudes to anatomy and death (Richardson, 1987). Other writers such as Brauer and Stafford consider the visualisations and representations of the physical body through art and art history (Brauer, 2010; Stafford, 1991).

In *Art and Science* Ede discusses works by different contemporary artists and considers how they have used and depicted the body. She cites the 2000-2001 exhibition *Spectacular Bodies: the Art and Science of the Human Body from Leonardo to Now,* to show how radically our attitude to the physical body can change. Discussing examples such as preserved foetuses in jars through to the grotesquely realistic wax anatomical mode, Ede suggests that the exhibition brought to the fore ‘a heap of glistening viscera’ (Ede, 2005: p.136). Ede then suggests that:

> ‘The presentation of the corpse in historical collections, whether whole, dissected or in component parts, is more profoundly strange because there lingers a sense of devotional reverence we can no longer share. (Ede, 2005: p.136)

These examples point to a move from the anatomically accurate but visceral visual representation of the physical body to ‘meat’ that is ‘clean’ and ‘cured and odourless’.

2.4 The Gaze: The Internal Body

Technology has allowed artists such as Mona Hatoum, Helen Chadwick and Marilene Oliver to explore the internal body through modern techniques of scanning, x-ray, MRI Scans and examination procedure such as endoscopies (Ede, 2005), thus creating artworks that use the visual output of technical data as the basis. Whilst artist Luke Jerram has made glass sculptures of viruses and microbes that invade and/or inhabit the body (Jerram, 2007). By comparison to the 'viscera', Ede argues that these technical works can produce an 'imagery so unyielding that they need explanation if they are to be understood' (Ede, 2005: p.137). It is these works that Ede describes as having the 'cool view' of medical scanning techniques. It is the 'cool view', the separation of 'person' from 'body' that seems to be a concern for many artists in the field. Artist Mona Hatoum suggests 'the body becomes vulnerable in the face of the scientific eye being probed, the ultimate violation of the human being' (Ede, 2005: p.147). In this case it is the machine that is probing the body and not the 'artists' eye'.

Volunteering herself as a subject in medical research artist Louise Wilson raises the issue of:

> The disturbing experience of separation between consciousness and the body, the sense of oneself as simultaneously both conscious subject and inanimate object, both sensate body and mere data. (Ede, 2005: p.147)

These concerns feed naturally into the reductionism argument often levelled at the sciences and in particular with the advent of genetic research that we are 'all just the sum of our genes' and have become 'information' banks of data (Anker and Nelkin, 2004). In comparing these different artistic interpretations of the physical body from the 'glistening viscera' to the 'cool view' demonstrates not only how our perceptions of the body have changed but also show the 'gap' that exists between the self and the physical body. This separation is magnified with the medical advances that have reduced the body to

molecular text. And whilst the 'basic theory of genetics is taught to every school child …that is not to say that it has become a natural part of our cultural language' (Ede, 2005: p.152).

2.5 The Gaze: The Absent Body

From the physical body being observed by the artists' eye to the observation of the 'eye' of the machine, the 'genetic artist' has a genetic printout, or a code of data. The view has shifted and therefore the terrain is harder to negotiate as we look for recognisable signs that we can interpret and find as something familiar. There is uncertainty expressed about the 'new genetic art' as Ede suggests that:

> Traditional media, such as pencil drawing or paint, are often more successful than high-tech images at communicating metaphorical meaning, perhaps because we can tune in to human agency, perception and inventiveness. We cannot see through the eyes of a machine but we can enter the artist's imagination and see through his/hers. (Ede, 2005: p.138)

Anker and Nelkin argue that the 'molecular vision' has 'displaced the visceral references' to describe the body (Nelkin and Anker, 2002: p.968). With 'genetic art', not only is the 'thing' that is being visualised invisible but there is also the nature of these visualisations themselves and the conventions attached to these that directly affect how we 'see'. Nelkin suggests that 'the gene in contemporary art has become a cultural icon. Genetic metaphors offer a way to represent the link between nature and culture' (Nelkin and Anker, 1996: p.60).

In *The Influence of Genetics on Contemporary Art* the authors outline what they perceive to be the three most common ways that artists exhibit the DNA molecule in artworks, these are 'as icon, as index and as symbol' (Nelkin and Anker, 2002: p.968). As index, DNA is identified as a pattern, most commonly as a black and white barcode that stands for a 'DNA fingerprint'. A criticism levelled at some work of this type is that by using

analogies between DNA coding, signs and information systems that are literal, the work becomes ‘all symbol – little meaning’ (Ede, 2005: p.153). These ‘codes’, Ede calls ‘extrinsic’, ‘tacked on’ and not ‘culturally involved’ (Ede, 2005: p.153). By comparison the work of Neal White, artist in residence at the Human Genome Mapping Project in Cambridge, is potentially more potent as White uses family photograph albums to demonstrate the heritability of human DNA (Ede, 2005). This ‘potency’ stems from the reinsertion of the human figure, the body, and the person rather than a series of symbols and signs that are not easily understood or ‘translated’ into decipherable language. This type of work elides itself to the ‘genetic portrait’ which has become a ‘new genre’ in art (Nelkin and Anker, 2002: p.968) and is based on the symbolic conventions of portraiture. In the ‘genetic’ portrait gene sequences which are unique to us all are used to represent the individual. Artist Kevin Clarke uses the letters AGTC and in doing so ‘eliminates the subject’s visual appearance and instead uses that persons genetic code’ (Nelkin and Anker, 2002: p.968) to represent the essence of the ‘sitter’. In the portraits, Clarke is ‘searching’ to define the essence of the individual. As he puts it: ‘What moves me is the confluence of notions of individuality, language, physicality and the development of a codex to describe a most elusive reality’ (Clark, cited in Nelkin and Anker, 2002: p.968). The DNA sequence to Clarke, is ‘the invisible made visible through an apparently simple genetic alphabet’ (Nelkin and Anker, 1996: p.57). Arguably the artist Marc Quinn takes things a step further by using actual human material in his work. Quinn’s two most commonly referred to works are *Self* (1999) and his *Portrait of Sir John Sulston* (2001). Whilst the ‘viewer is entertained’ by such works, arguably they evoke little more than ‘a ghoulish chuckle’ (Ede, 2005: p.137). In contrast Kemp suggests that Quinn’s genetic portrait of Sir John Sulston ‘shows that some artists engagement with DNA is maturing beyond iconographical opportunism’ (Kemp, 2003: p.420). These works can therefore be seen as controversial and can also elicit a mixed response. The ability to visually interpret what we are seeing would seem to rely on how much or how little narrative structure surrounds the work. The transference of factual information - how things work and fit

together – through code or data gets lost in translation and we rely on more familiar references for recognition e.g. a physical form. Taking an art historical approach Kemp suggests:

> Every act of looking is an act of active interpretation...when we are confronted with unknown sights in visual landscapes of which we have no prior experience, the complex interaction between seeing and knowing becomes openly problematic. (Kemp, 2000: p.42)

The genetic code is a string of information and it is this 'information' and the visualising of such that permeates the work of many contemporary artists concerned with the area of genetic research. The 'information' was first referred to as such by Watson and Crick when they said that the genetic structure they had discovered was an 'information system' (Doyle, 1997). For a visual representation of this 'information' Watson and Crick built a model of the structure of the DNA molecule. It is this structure of the double helix that initially commanded the visualisations of artists attempting to interpret something that had become 'a molecular vision' and that had begun to 'dominate the theories and methods of the biological sciences' (Lumsden and Wilson, 1981).

2.6 The emergence of icons: The Double Helix

The double helix has become an iconic image in the debates and visualisations of genetic research, perhaps only recently falling out of favour as Denna Jones, curator of the Wellcome Trust's Two10 Gallery in London, put it 'anything to avoid the wretched Double Helix' (Ede, 2005: p.153). For an artist's visualisation of the DNA structure it is Salvador Dali who is generally acknowledged as producing the 'first' work of art that depicted the double helix as a in "*Butterfly Landscape (The Great Masturbator in a Surrealist Landscape with DNA)*", which he painted in 1957-58. Significantly the double Helix is now prevalent not only in the visual arts but also as a 'logo' for the sciences and the media.

Nelkin states that scientific visualisations are ‘appearing in both the multi-layered genre of high art and the more direct iconography of media illustration’ (Nelkin and Anker, 1996: p.56).

In his *Nature* magazine article, Kemp (2003) attempts to unpick the iconic status that the double helix structure has reached. Interestingly he uses Leonardo Da Vinci's *Mona Lisa* as a comparable model and states that, as the *Mona Lisa* epitomises the ‘super image’ something that has ‘transcended its original context and insinuated itself into our visual consciousness’, so the double helix structure goes unchallenged as ‘epitomizing the biological sciences’ (Kemp, 2003: p.416). He goes on to suggest that Watson and Crick are ‘identified with DNA no less than Leonardo is identified with the *Mona Lisa’* (Kemp, 2003: p.416). An important point made in this article is that Kemp sees the scientists (Watson and Crick) as ‘authors’ or ‘artists’ of the ‘acts of visualisation that generated their models of the molecule’ (Kemp, 2003). This type of reference to the visual ‘output’ of the scientists is often referred to in the literature. In the Forward to *The Molecular Gaze* by Anker & Nelkin, Philip Reilly, a scientist, rather enthusiastically refers to a photograph taken after the research discovery by Crick and Watson was published in the *Nature* paper in 1953. The photograph shows the two scientists, who Reilly refers to as ‘molecular architects’, with their ‘sculpture’ of the Double Helix structure (now residing in the British Museum) along with the sketch of the DNA strand drawn by Odile Crick and published alongside the original paper. Reilly’s enthusiasm is for the ‘three artistic mediums’ captured together in the one image (Anker and Nelkin, 2004).

2.7 Crossing Borders

These observations would seem to bear out the arguments of those intent on finding answers to the earlier questions posed by Kemp and Ede that perhaps one discipline can be interchangeable with, or become a substitute for, the other. This general thesis is put

forward by Evelyn Fox Keller, writing about the language of science. Using the expression 'trafficking across disciplinary borders' (Keller, 1995: p.18) within a biological science context, she suggests that this 'boundary crossing' can provide both 'risk' and 'opportunity' as part of 'disciplinary transgression' (1995). In the same way, the visual structure of the double helix 'transgressed' the disciplinary boundaries of art and science to become a 'portrait' representing the basis of all life. Whilst the majority of 'genetic' art has voiced serious cultural and sociological concerns about reductionism/determinism, eugenics, and gender, there is also a seam of work that seeks to cross these 'borders' and exchange 'intellectual' resources for the purpose of explaining and communicating this often difficult and complex information.

If through these 'visual images' a representative 'language' is created then it is this 'language' that Nelkin suggests 'we are all then trying to unpick/unravel/transcribe and decode' (Anker and Nelkin, 2004). In *The Molecular Gaze,* Anker and Nelkin argue that there are five main themes that dominate the 'genre of genomic art'. The authors outline these themes as; the reduction of the body to molecular text, the meaning of mutation, the blurring of species boundaries, the notion of perfection, and the co modification of nature. Through these themes there are emerging arguments about reductionism, eugenics and gender as Nelkin suggests that 'for artists genetic metaphors are a way to represent the inner essence of a person, the truth behind appearance, the nature of authentic self' (Nelkin and Anker, 1996: p.57). Focussing on the re-emergence of Chimera in both art and biology, Anker states that these 'experiments' break species boundaries and 'change our relationship to living matter' (Anker, 2000: p.372) and in a chapter entitled *Mutation, Manipulations, and Monsters: The New Grotesque in Art,* (Anker and Nelkin, 2004) Nelkin discusses the 'fear' surrounding mutation and Ede states that we have a '…fearful fascination with the mutant and monstrous...making solid the nightmares of distortion and uncontrolled mutation (Ede, 2005: p.155). These arguments are all rooted in the ideas generated by genetic research in the ability to cure diseases through medical treatments based on genetic interventions. Whilst some genetic art is concerned with visualising

‘grotesque’ and ‘mutated’ forms which can suggest ‘breeding better people’ and the ‘resurfacing of the eugenics movement’ (Anker and Nelkin, 2004). This type of art work functions in a landscape of ‘imagined horrors’ that seek to question ‘just how far the science of genetics can and will go’ (Ede, 2005).

There are other artists however, who explore through their works the realities of mutation in terms of disease and illness. These works endeavour to enter into a dialogue with how the transference of difficult diagnosis and the potential of the physical threat of disease can be communicated and interpreted. This struggle with the ‘language’, here referring to the visual as well the linguistic, is illustrated in a quote from artist Andrea Duncan. During a collaborative work Duncan undertook a three-year residency with the Department of Haematology at Kings College Hospital where she collaborated with clinical staff and patients with leukaemia...she was intrigued by the way in which staff and patients describe the same experience in two seemingly irreconcilable languages (Ede, 2005).

> ‘Specialist languages and terminologies are reduced to a series of acronyms constellated around a diagnosis...information is processed too fast for meaning. Is language adequate to deal with both the physical metamorphosis and sense of suspended animation, which the illness imposes? (Ede, 2005: p150)

Duncan made a number of works which appropriated ‘genuine medical record material’ in ‘attempts to make order out of disorder’ (Ede, 2005: p.151). Artist Nancy Burson explores the meaning of ‘normality’ with documentary photographs of children with rare genetic conditions that cause craniofacial disorders in order to ‘demonstrate the difficulty in defining normality and disease’ (Nelkin and Anker, 1996: p.57). In her works *Progressive Disorder* (2000) and *Endless Walk* (1999), Christine Borland takes found historic images, etchings and drawings, by clinicians who have depicted patients with inherited genetic diseases, such as Duchenne muscular dystrophy, and animated them (Borland and Brown, 2001). Whilst Jacqueline Donachie in her work, *Tomorrow belongs to me* (2006), explores the logistics of inheritance.

Contemporary artists working with the body and representations thereof have acknowledged advances in technology and produced works like those of Marilene Oliver with MRI scans in the work *Family Portrait*. American artist Suzanne Anker references a genetic read out in her work Zoosemiotics (1993), and works such as HeLa (2000) by Christine Borland utilise laboratory methods of visualisation for the installations. All of these works use a combination of 'real' scientific data or images appropriated into the works. But all of them also generate the 'humanness' of the subject – the 'person' who has the mutation.

The visualisation of genetic research and its meaning through the visual arts is complex. George Gessert, suggests that 'the terrain of art involving genetics, DNA and biotechnology' is difficult to navigate partly due to the 'profound social and ethical challenges' surrounding this area but also 'because the art under consideration does not comprise anything like a traditional school or movement' (Gessert, 2005: p.67). And Fox Keller argues that whilst 'art can function as a form of cultural critique, expressing cultural anxieties, disrupting conventional platitudes, transgressing accepted boundaries' (Keller, 2004: p.817) genetic art can also be prone to what she refers to as 'functional ambiguity'. For whilst artworks of this type often set out to 'explain' and 'visualise', these expectations are not necessarily met and or understood (Keller, 2004: p.187).

There are many art science collaborations; two recent projects, the *Design4Science Projec*t (Wheeler, 2007) and the *Designs for Life Project* (Harrison, 2008) both set out to use art as a means to 'visualise' aspects of science. The *Design4Science Project* (design4science, 2007) with a publication (Wheeler, 2007) and an exhibition was about 'visualising the invisible' of molecular biology. For this, artists and designers were invited to 'respond to' scientific discoveries. The exhibition associated with the project used the models, drawings, illustrations and photographs that had been made at the time of a particular scientific discovery by scientists and or illustrators. For example the watercolours painted by Irving Geis of 'Myoglobin' 1961 and the drawings created by John

Sulstan while researching the cell division of a nematode worm under the microscope in 2002. It is noted in the accompanying text by Wheeler and Long, that ‘What is most extraordinary about Sultans’ research is that he almost exclusively used watching and drawing’ (Wheeler, 2007: p.64).

The project explored the visualisation of the science, by scientists and the artistic techniques used to do so. The second part of the exhibition consists of the artistic response to the scientific discoveries made by artists and designers. Stated in the text of the accompanying publication the point is made that ‘there was no demand in the brief to give ’technical’ explanations of the science,’ (Wheeler, 2007: p.71) but rather:

> The intention here was to take a creative sideways look and have the opportunity to make new connections that may open windows on fresh perspectives for science and in particular, molecular biology. (Wheeler p71)

In the same vein the *Designs for Life Project* was set up to:

> Explore the process of visualisation of laboratory data relating to aspects of cell and gene research. Through a series of production collaborations and integrated public engagement the project aims to stimulate debate at the confluence of science and visual culture. (Harrison, 2008: p.5)

The Designs for Life project brought scientists into the art studio, in this instance the print studio, to collaborate with artists to make artworks that were visualisations of the laboratory processes and outputs. Harrison advocates that ‘art has an important role to play, as a vehicle for discussion and communication’ (Harrison, 2008: p.6) in the context of genetics and the biosciences. Both of these projects illustrate the separation between the distinct cultures of art and science and investigate what happens when the two disciplines come together. As Harrison points out:

> Despite the recent increased interest in artscience [sic] activity however, it remains evident that the prevailing view of this relationship is one of segregated disciplines or even of distinct cultures existing in their own domains. (Harrison, 2008: p.10)

2.8 Integration: Methods and materials

There are examples of artists who produce what is often termed Bioart[6] a phrase attributed to Eduardo Kac when speaking of his work. Bioart can be defined as art 'using biological materials' or 'wetware' as it's medium (O'Riordan, 2010: p.82) with Kac's work *Alba* (2000) the GFP Bunny that glowed green, as being one of the most well known examples. Helen Chadwick used laboratory material in the form of rejected embryos in her work, *Unnatural Selection* (2006), whilst the artist Stelarc grew a third ear on his arm using human cells in 2007. Mark Quinn's sculptural work *Self* (2006), a bust of himself made from own blood and his 2001 portrait of Jon Sulston both use 'wetware' as their medium. Sulston, a biologist who played a central role in the human genome sequencing project, commented on the portrait 'It's not me. It's my starting point' (Sulstan, 2000, cited in Anker and Nelkin, 2004: p.42). The portrait was unveiled at The National Portrait Gallery in London in 2001 and consisted of a small mirrored frame in which was an agar gel containing Sulston's DNA that had been extracted from his sperm. The resulting portrait presents a detail of Sulston's genome - the 'recipe' to make him and is described by journalist Jonathan Jones as:

> Beads of transparent matter hang in a cloud under glass. The constellation of tiny forms, catching the light, is suspended in a silver frame, as if it were a religious icon... it's a kind of organic jewellery, a gossamer presence at once barely visible... (Jones, 2001)

Commenting Quinn said:

> What I like about my portrait of John Sulston is that, even though in artistic terms it seems to be abstract, in fact it is the most realistic portrait in the Portrait Gallery since it carries the actual instructions that led to the creation of John. It is a portrait of his parents, and every ancestor he ever had back to the beginning of Life in the universe. (Jones, 2001)

[6] For a full discussion of examples of Bioart and Sciart in the context of Art and Genomics see O'Riordan K. (2010) *The genome incorporated : constructing biodigital identity,* Farnham: Ashgate.

Those interviewed for the launch all seemed to think that the portrait posed some rather big questions. Jones asks:

> The portrait is the result of a standard laboratory procedure, transposed into the setting of the Gallery. Does this change of viewpoint alter our perception of the object, and of the techniques that give rise to it? (Jones, 2001)

As Charles Saumarez Smith, Director of the National Portrait Gallery suggested one of the 'great strengths' of the work is that it asks the question 'what is a portrait? What is a person?' (Jones, 2001)

The *QJM* and *Nature* magazine both ran a comment on the work. Martin Kemp, writing in *Nature* magazine argues that it is not so much a 'functioning' portrait but a 'kind of relic set in a precious vessel' and that there is:

> A frisson of awareness that we are in the presence of something that is really part of the actual person rather than a mere optical record at one or more removes from the physical original. (Kemp, 2001: p.778)

Whilst acknowledging that the 'individuality' of the portrait is incontrovertible this 'level of individuality is not readily accessible to the spectator', thus what the portrait fails to do is 'serve as a wider exemplar for a new genre of individualising portraiture' (Kemp, 2001). Christopher Martyn, writing an editorial in the *QJM*, commented that whilst the press release from the National Portrait Gallery hoped to 'prompt the viewer to consider his or her own identity' he suggested that for some it will lead to 'frustration' as the portrait contains 'enormous amounts of undecipherable, personal data.' He went on to say that 'it's as if the artist has failed to appreciate the difference between information and data, a bit like mistaking a list of ISBNs for the contents of a bookshelf' (Martyn, 2002). This portrait, held within its relatively tiny 5 x3 3/8 inch frame is, according to the National Portrait Gallery catalogue, an 'accurate display of Sulston's essential identity since it is composed of his own DNA' (Jones, 2001); it is also the 'recipe' and 'instruction' to make a human being and the 'archive' of those that have gone before and it poses questions of identity and individuality. Yet whilst all of these ideas, some would say facts, are evoked by this work we cannot actually see anything except a mirrored frame (within which we

might see our own reflection depending on the position of the viewer) and ‘transparent’ matter ‘catching light’.

2.9 Ways with Words

It was reported in the journal *Nature* (Pearson, 2006) that Simon Shepherd, a Professor at the University of Bradford had used the text of the novel *Emma* by Jane Austin to test a computer programme he had written to construct an algorithm that could unpick the sequences of the letters A,T,G,C in the Human Genome. By removing all of the spaces and punctuation from the novel, the algorithm ‘despite having no knowledge of the English vocabulary or syntax was able to identify 80 percent of the words and separate them back into sentences’ (Pearson, 2006: p.259). Whilst here the scientist uses the literature as a test bed for a computer programme the performance poet, Christian Bök, created what he called *The Xenotext* (Bök, 2008).

> "*The Xenotext Experiment*" is a literary exercise that explores the aesthetic potential of genetics in the modern milieu - doing so in order to make literal the renowned aphorism William S. Burroughs, who has declared that "the word is now a virus." I am proposing to address some of the sociological implications of biotechnology by manufacturing a "Xenotext" - a beautiful, anomalous poem, whose "alien words" might subsist, like a harmless parasite, inside the cell of another life-form. (Voyce, 2007)

The content of the experiment was for Bök to write a poem that is then ‘translated into a gene sequence’ and then implanted into an organism. Bök explains that the implant causes the bacterium ‘to produce a viable protein in response’, that when translated is ‘a completely different poem’ (Condliffe, 2011). The reasoning behind the work for Bök is to ‘infect’ the language of genetics with the ‘poetic vectors’ of its own discourse, doing so in order to extend poetry itself beyond the formal limits of the book (Voyce, 2007).

Eduardo Kac has, likewise, used a genetic process of encipherment for creative purposes in his artwork entitled *Genesis (1999):*

> Kac has transformed the biblical sentence, "Let man have dominion over the fish of the sea and over the fowl of the air and over every living thing that moves upon the earth," encoding this phrase into a strand of DNA, which has then implanted into a microbe, subjecting the germ to doses of ultraviolet irradiation so as to cause mutations in the text itself as the microbe reproduces and multiplies. (Voyce, 2007)

Works such as these adopt quite literally the processes of science in order to transgress the boundaries of the two cultures of art and science to such an extent that the boundaries themselves become blurred.

3 *Seeing*: The visual imaginings of disease

> The idea of representing the diseased through visual images reaches back through the ages. The act of 'seeing disease'…is socially coded in many complicated ways. To decipher this code one must be able to reconstruct the patterns that dominate and shape the perception of the patient, the sufferer of the disease. (Gilman, 1988: p.3)

3.1 Introduction

This chapter focuses on the ways in which genetic diseases, in this context Neuromuscular Diseases, are visually represented in historic medical photographs and contemporary laboratory diagnostic techniques, and explores how the differences in these visual representations impacts on the understanding of what is being 'seen'. The narratives that are constructed around these images, in terms of how we make meaning from the visual, is investigated and considered within the historical and cultural contexts in which the images were/are created. This understanding has been key to this research project as, through studio practice and in particular the combining of historic photographs with diagnostic images, representations have been created to represent, in essence, that which is invisible. Significantly, Duchenne muscular dystrophy is caused by the lack of dystrophin expression in the body. It is initiated by the absence of a specific substance that is then visualised in order to be interpreted and understood. Through visualising and physically making interpretations of this kind of metaphorical communication, this research articulates a discourse between the *seeing* and the *saying* and engaging with the idea put forward by Roland Barthes in Camera Lucida that: '*…*a photograph is always invisible: it is not it that we see' (Barthes, 1993: p.6).

3.2 At First Sight

There is a photograph of a boy, he is a young boy, and he fills the frame of the picture. There is an adult standing to the side of the photograph and all that we see of the adult is the arm and part of the torso. The boy is naked and the arm of the adult is clothed. The adult is wearing a jacket; we can see a white shirt cuff at the wrist and what appears to be a watch chain at the waist. The clothing would suggest that the adult is a man. The boy is standing on something; this makes him taller than the adult as the adult's arm is reaching up. The boy stands in profile but slightly turned away from the camera, the pronounced curve at the small of his back makes his buttocks and his belly project out. His left shoulder blade protrudes slightly as his arms are bent at the elbow as if his hands are up and under his chin. His legs look well-muscled, his calves are large and the curve of his thigh muscle is clearly visible. The boy's face is a blur. This is what we see at first sight of the photograph.

Figure 2 Joseph Sarrazin Duchenne GB. (1862) Album de photographies pathologiques: complémentaire du livre intitulé De l'électrisation localisée*:* J.-B. Baillière et fils

The ‘story’ of this photograph can be ‘told’ through various means. The photograph is of Case Number 68. The boy in the photograph was named Joseph Sarrazin and he was approximately seven years old when the photograph was taken sometime early in the year 1858. He died of tuberculosis at the age of fourteen years old. Joseph Sarrazin was the first case, of what became known as Duchenne muscular dystrophy, to be seen and recorded by Duchenne de Boulogne (1806-1875) a neurologist working in Paris.[7] The patient ‘presented’ at the private clinic of Duchenne de Boulogne with ‘difficulty in learning to stand and walk’ and ‘weakness in his legs’. This ‘weakness’ was contrary to the appearance of the muscles in the legs and Duchenne commented that ‘I was not a little surprised to learn that these athletic appearing muscles had been lacking power since birth and had hardly been exercised’ (Tyler, 2003: p.409). It is likely that the photograph was taken in the clinic of Duchenne and it is possible that the adult present in the photograph is Duchenne himself. The ‘story’ of this photograph and therefore the ‘stories’, in part, of the individuals in the photograph can be narrated in this way until the sources of information and factual accounts of the time are depleted. There is, however, another ‘story’ held in this image and it is this ‘story’ that the physical body of Joseph Sarrazin was writing.

If a boy like Joseph Sarrazin ‘presented’ to a doctor today he would be diagnosed with the genetic disease Duchenne muscular dystrophy. Over 150 years after Joseph Sarrazin, the prognosis for a contemporary patient with Duchenne muscular dystrophy is not that different as there is no known cure for the disease. There is however, much more now known of the ‘story’ of the disease and it is how this ‘story’ is told, both visually and linguistically, that is the focus for this research. How we ‘see’ disease is not just the visual interpretation of ‘signs’ of disease i.e. how the disease physically manifests itself, (in this case the physical manifestation of ‘weakness’ which we cannot actually ‘see’ in this

[7] For a full history of the life of Duchenne de Boulogne and the controversy surrounding the ‘discovery’ of the disease see Emery AEH. (1995) *The history of a genetic disease : Duchenne muscular dystrophy or Meryon's disease,* London: Royal Society of Medicine Press.

photograph), but how we see and interpret this image is embedded in the visual and linguistic culture of the viewer (McGrath, 2002; Stafford, 1991; Gilman, 1988).

At first sight the viewer of this photograph may note that something is 'wrong' with the boy. The very nature of the manner in which he is 'displayed' for the camera invites the viewer to 'look'. The question of what we are looking for and if this 'thing' is visible or not remain unanswered. In an essay discussing the interpretation of the physical signs of illness and disease, Jane Macnaughton suggests that 'aesthetic judgements are integral to our decisions as to whether physical appearances are right or wrong' (Macnaughton, 2008: p.76). The 'everyday' language that we use to describe illness or disease is inherent in comparisons between what is considered healthy and what is not. Macnaughton argues that we have an 'aesthetic template' of what we consider to be healthy 'but those healthy or desirable templates can be affected by influences from the societies in which we live' (Macnaughton, 2008: p.78). Whilst the definition of what is healthy or not may change across culture and society and over time, there is a fundamental categorising of what is 'right' and 'wrong', 'normal' and 'abnormal', and 'healthy' and 'unhealthy' that constantly exists. As Lupton argues:

> Over the history of western medicine, visual representations of illness have played an important political role in the categorising of the *Other*, those deemed abnormal or dangerous to society. (Lupton, 2003: p.76)

Historically the *Other* in society was manifest in many forms. Not only in the physical presentation of abnormality caused by disease but also in the categorisation across society of what was considered to be 'normal'. 'Difference' or *Other* was therefore scrutinised and catalogued for comparison. This scrutiny and cataloguing of 'sameness' and 'difference' took place across a broad spectrum of disciplines that were not just concerned with health and illness, but also with the visual representation of what was deemed to be the 'truth' of the human body (Brauer, 2010; McGrath, 2002). In a public lecture entitled *Dissecting Art, Science and Medicine*, Brauer, argues that 'art, science

and medicine have become so inextricable intertwined that it is impossible to separate the history of art from the histories of these other disciplines' Brauer goes on to argue that with these disciplines 'reinforcing one another from the times Vesalius began public dissections the body was turned into a spectacle' and it, (the body) became 'the prime object of the gaze' (Brauer, 2010). Throughout the lecture Brauer uses historic paintings to construct a visual narrative of how the physical body was made public and to illustrate the power positions that exist(ed) around the body, suggesting that:

> …the human body became the measure of all things during Renaissance Humanism many physicians and artists maintained that the only way to find out about the mechanisms of the body was to dissect it…as optimized by the work of Leonardo de Vinci. (Brauer, 2010)

The physical body becomes not just the 'object of the gaze' but also the site at which to 'find out', 'the bodily interior is widely understood to make visible the 'truth' about that body' (Stephens, 2011: p.3). Stephens goes on to suggest that 'a high evidentiary value is thus attributed to images of anatomy: it is in seeing the interior of the body that we see its' truth' (Stephens, 2011: p.3).

The 'Body Worlds' exhibition by Gunther Von Hagen seems to epitomise this fusion of art and science for whilst Body Worlds is fundamentally an 'art' exhibition it also, as Stephens argues, adopts many other cultural conventions such as those of the *Freak Show* and the *Educational Exhibition*. With the publicity for Body Worlds, as Stephens points out, being 'designed in such a way that visitors experience it much as they would a three dimensional text book' (Stephens, 2011, p.3). Both Brauer and Stephens argue that the 'spectacles' of the display of human anatomy and dissection not only 'flourished' as forms of 'popular entertainment' but also reinforced the relationship between art, medicine and science. The physical body, dissected and displayed, became the site for popularising new ways of seeing and understanding, and therefore a way of gaining anatomical knowledge and information about health and wellbeing. However, the methods of display used for the body and the visual narratives and depictions of the patient/doctor and

crime/punishment scenarios require the artist for interpretation and the visual narratives to emerge. The ‘spectacle’ of the public dissection theatre and the power related enforcement of medical knowledge for consumption by the masses is played out through, as Bauer argues ‘the art school, the clinic and the laboratory’ all being inextricably linked. Whilst the act of dissection, as discussed by Brauer and Stephens, allowed for an intimate seeing of the truth of the physical body and of a way to ‘find out’ about the internal workings of the body, the diseased body was often examined in that of a patient who was alive and so therefore dissection, as a method of seeing was not possible. Thus the representation of the physical body, either in a ‘well’ or a ‘sick’ state was normalised through various forms of visual representation that included painting, drawing and photography.

In his book *The History of a Genetic Disease*, Alan Emery, attempted to trace the history of the visual depictions of diseases like Muscular Dystrophy by identifying what could be signs of this type of illness. Emery suggests that figures depicted on the wall of an Egyptian tomb (circa 2800-2500 BC) could be that of a boy with muscular dystrophy. The boy, Emery observes, ‘has lost the normal arch of his feet (which is usually clear in Egyptian wall paintings); his calves are somewhat enlarged and he may have some degree of pseudohypertrophy of certain upper limb muscles’ (Emery, 1995: p.9). There are other early artworks that Emery draws on; Raphael’s *Transfiguration* (1520) and an engraving by Hieronymus Cock (c.1520-1570) titled *Beggars,* both of which could depict a sufferer of muscular dystrophy. Whilst Emery concludes that these observations are ‘speculative’ it is testament to the fact that the visual depiction of disease through artistic endeavour is a valid resource in tracing the history of disease.

It is well documented that historically, under the ‘medical gaze’ the physical body has been recorded through the use of different art forms; through close anatomical observation, dissection, drawing and écorché figures. The use of portraiture to depict ‘sameness’ and ‘difference’ and in this context portraits of those diseased can be

illustrated by works such as those of Lam Qua (1801 -1860), the first Chinese portrait painter to be exhibited in the West. Lan Qua's medical portraits are of patients with large tumours or other major deformities. Whereas historically the 'types' of human could be attributed to physical comparison in work such as that of Galton who, Martin Kemp argues, completed, 'the most impressively systematic of all the projects to use photography in the service of new sciences for humankind' (Kemp, 1997: p.130). In his work, *Inquiries into the Human Faculty* of 1883, Galton aimed to define 'an all-encompassing science of human heritable attributes' (Kemp, 1997: p.131) It is this work that established the term eugenics.

Clinicians such as Duchenne and Curschmann used not only photography but also drawing and etching to depict the patients that they saw in their clinics. Gower's used line drawings to record the symptoms and changes that occurred in those he was trying to treat, whilst Duchenne used various artistic means to record the physical symptoms of the patients that he was observing in the clinic.

Figure 3 *Four brothers* Curschmann H. (1894) *Klinische Abbildungen.* Berlin: Julius Springer

More contemporary publications showing the manifestation of the muscular dystrophies through the use of medical portraiture can be seen in books by Victor Dubowitz, such as *A colour atlas of muscle disorders* (1989) and *Muscle Disorders in Childhood* (1989). These books contain images of patients that show the progression of the disease overtime and how this affects the movement and physical degeneration of the body. As is common in more recent use of this type of image the eyes of the patient shown in the photograph are often blacked out.

The use of the moving image to record the human condition can be seen in the works of Eadweard Muybridge (1830-1904) whose work on *Human Locomotion* recorded the physical body by way of the moving image. As Kemp points out it was Muybridge who went 'beyond the recording of the static posture' to 'create living inscription of the irregular gaits of those afflicted by anatomical and motor disorders' (Kemp, 1997: p.147). Exploring the relationship between the visualisations that emerge from both the art school and the medical school further, an example is that of the painting by Francis Bacon of *Paralytic Child Walking on all Fours* (1961). This painting is a depiction of images from the 1887 film by Muybridge of the same name. It is likely that the boy in the Muybridge film has been afflicted by polio and in the *Album de photographies pathologiques* (1862) by Duchenne there is a photograph of a very similar boy [Fig.5]. In these examples we have the visual depiction of the same disease in the photographic portrait, the moving image and the painting.

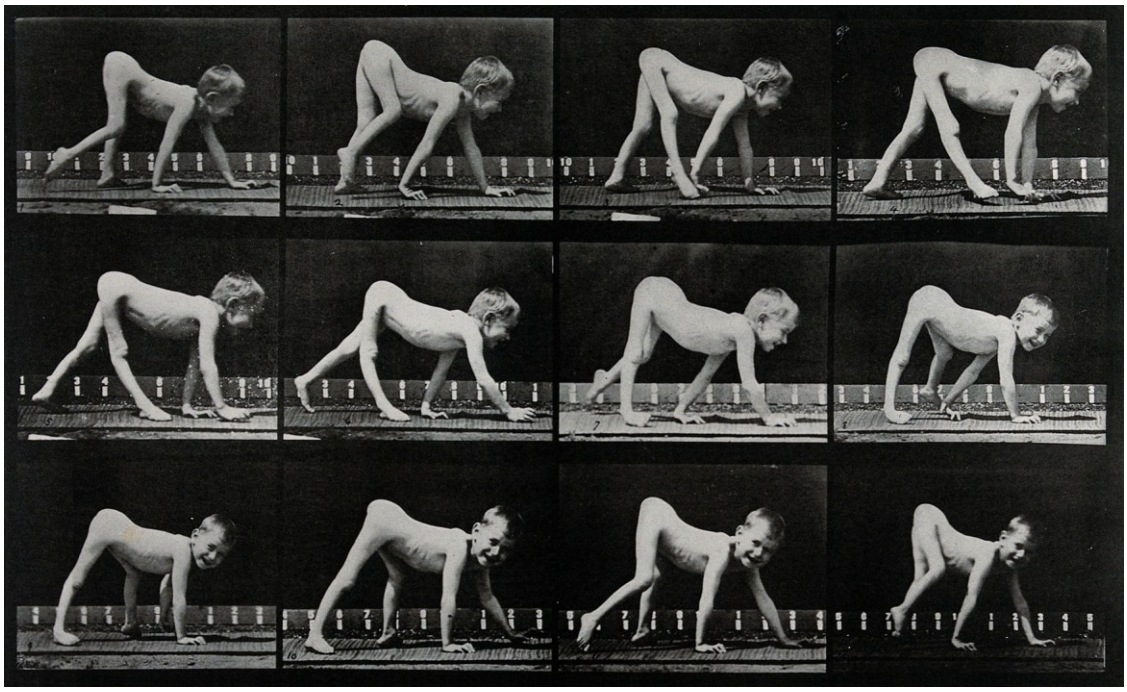

Figure 4 *Plate 539 (Infantile paralysis child walking on hands and feet)* Muybridge (1887) Wellcome Library, London

While modern methods of communication technology allows for instant and random access to the visual depictions of disease via the internet, the TREAT-NMD website, whilst carrying a substantial amount of information for those afflicted by and or interested in the neuromuscular diseases carries few images that could be seen as visualisations of the disease itself. The images that are included on the website are akin to 'library' science images showing laboratory equipment and medications. The images that include people tend to show young children with adults looking happy and smiling. The children in these images do not display any signs of disease or illness.

Figure 5 Plate 12 *Duchenne GB. (1862) Album de photographies pathologiques: complémentaire du livre intitulé De l'électrisation localisée*: *J.-B. Baillière et fils*

The *Life Thru a Lens Project*, (Life thru a lens, 2009) was an arts project that was organized by the charity Action Duchenne in 2009, with an exhibition of the works created being held in the Bio Science Centre at the Centre for Life in Newcastle upon Tyne. Using the medium of photography, and in particular portraiture, those affected by Duchenne muscular dystrophy made a photographic record of living with a disease. The aim of the project was to bring the condition 'to the public eye'. The images that were created for this project, by the sufferers themselves, depict the physical body 'presenting' with the symptoms of the disease in a real and intimate manner. Images such as these are not often made available to the public through a medical environment and this exhibition chose the medium of photography in order to accurately record that which the participants wanted and were prepared to reveal about their lives with Duchenne muscular dystrophy. These contemporary images in the context of actually showing the physical manifestation of the disease are therefore much closer, in terms of content, to the historic photographs like those of Duchenne and Curschmann but are displayed with the permission of the sufferer rather than in the interest of the 'clinical gaze'.

Figure 6 *Self Portrait* Stuart Wickison *(2009) Life thru a lens: photographing life with Duchenne*

In the *comparison* of one thing to another, through a physical similarity or difference the accepted norms evolve and therefore definitions of what is considered to be 'healthy' or 'unhealthy' and consequently 'right' or 'wrong' can be measured. Macnaughton argues that there are different 'senses' of what health is; it is the 'bodies status quo', a way of saying that 'we are not ill or diseased' (Macnaughton, 2008: p.73). She further suggests that 'medical practice seems to support this view of health, in that the treatment that restores us to health is really just removing disease or illness' (Macnaughton, 2008: p.73). The other 'sense' of health is that defined by the World Health Organisation as: Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity (Macnaughton, 2008: p.73). Given a definition(s) of what health is we can return to the photograph of Joseph Sarrazin and 'look' again with the knowledge that he may or may not be healthy. By recording images such as this one and then by making comparisons between such images and the considered norms of society it becomes possible to 'see' in a different way than just *'seeing'* what is visibly present, for we begin to 'see' something other. In this case we are 'seeing' a disease, the 'story' of which is still

under construction as at the time of this image being recorded there were more questions than answers available to clinicians like Duchenne de Boulogne.

3.3 Truth & Reality

The advent of photography in 1839 'signalled a new era in medical representation' (Kemp, 1997: p.120). The process presented 'a perfect and faithful record' (Kemp, 1997: p.120) at once removing any problems of 'subjective errors' and 'artists fallible perceptions'. The use of photography as a way of 'showing' and 'seeing' disease became prevalent and clinicians such as Duchenne used this method extensively to record and catalogue the research and diagnosis of patients with disease. Patients were photographed 'displaying the marks of their illness…in the interests of the clinical gaze' (Lupton, 2003: p.76).

In the mid nineteenth century notions of thinking about the photographic image were very much to do with the 'truth' of the image, Duchenne referred to it as a 'perfect mirror' of reality (Tyler, 2003). Some fifty years later in 1894 Heinrich Curschmann produced a book of clinical illustrations *Klinische Abbildungen* (1894). This collection of photogravures was presented as 'a collection of portrayals of changes to the outer corporeal form by internal disease' (Curschmann, 1894). In the preface to the book Curschmann wrote '…it shall be just the pictorial rendering that is of paramount importance. The text shall only validate and enhance its usefulness as a teaching aid' (1894). The physical manifestation of disease and the ability to view and capture an image of the disease is integral to diagnostic medicine. As Lupton suggests:

> The body has historically been the site at which reasons for illness were interpreted. The sick body is a meaningful text; its signs and symptoms present a map for understanding. In pre modern times, the sick body vividly presented itself as suffering the mortifications of the flesh. (Lupton, 2003: p.106)

Through the collection and documentation of images of diseases not only were patients compared and contrasted in order to look for causes and cures but also these images fed into what were considered to be the way in which certain diseases may present within a patient. The photographing and recording of the visual disease is still 'central to medical literature…whilst patient faces are perhaps not shown as freely now as they were' (Lupton, 2003: p.76). For Gilman 'the portrait of the sufferer, the portrait of the patient, is therefore the image of the disease anthropomorphised', (Gilman, 1995), the body is a 'text' to be read. This idea of 'reading' the body as a text is reinforced by Curschmann in the forward to *Klinische Abbildungen,* in that for him, the photographic images show the outward changes that are made, and the traces that are left by the internal disease. The outward signs on the physical body tell the story as, in the case of muscular dystrophy, the disease manifests itself through the 'absence' of something (dystrophin) rather than the 'presence' of something causing the disease. This genetic mutation is intrinsic to the physical body as opposed to other forms of disease i.e. cancers that are seen as 'invading' the body, the mutation is part of the 'story' that the body is writing through the transcription of the DNA.

3.4 Intention: How we see

Whilst in essence the photograph is '…a process of chemical transcription' (Kemp, 1997: p.120) and, as Berger points out, the 'primary raw materials (of a photograph) are light and time' (Berger, 1972) the photographic image still represents something other than can be physically 'seen'. As Bathes argues '…a photograph is always invisible: it is not it that we see' (Barthes, 1993: p.6). So how do we know what we see? Kemp suggests that questions about this truth revolve around the:

> …advertent and inadvertent intentions of the person or persons doing the recording, and the relationships between these intentions and the viewers of the imagery, envisaged and actual. (Kemp, 1997: p.121)

The thesis that Barthes puts forward in *Camera Lucida,* that he names *Studium* and *Punctum,* can be considered to revolve around the idea of intention. For Barthes the *Studium* is the intention, the gaze of the photographer (*the operator*), whereas the *Punctum* is the disturbance to the gaze that occurs for the viewer. It is this disturbance to the 'story', the narrative structures created around images that this research explores.

These 'intentions' are complex for whilst the 'advertent' intention of clinicians like Duchenne was to create a true image, a 'mirror' of reality of the physical manifestation of the diseases that were presenting in his patients, with the advancement of modern technology there has been a shift in the visual representation of disease and therefore how we 'see'. For Duchenne de Boulogne the cause of the 'weakness' in the muscles of Joseph Sarrazin was unknown and whilst he could photograph the boy and compare his physical presentation with what could be considered as 'normal' and/or 'healthy' for the time, Duchenne had no way of being able to 'see' the underlying molecular cause of the disease. In this case, that of Duchenne muscular dystrophy, the cause is further complicated by the fact that the disease presents because something is 'missing', as the condition is caused by the absence of dystrophin. As medical technology is employed in more and more contexts, the emphasis upon 'discovering' hidden disease in the body has 'intensified' (Lupton, 2003: p.106). This assertion by Lupton is borne out of not only advancing technologies but also the speed at which these technologies have changed the terrain, of in this context, the biological sciences:

> Modern medical technology has become increasingly concerned with describing the human body in a code…the letters C, A, G and T. The body here described is an abstraction – a statistical or diagrammatic averaging of the body rather than a reflection of the true complexity of living, breathing, interacting flesh in the world. (Macnaughton, 2008: p.83)

Historically the physical body was very 'present' in visualisations, be that through sculpture, anatomical drawing, painting, public dissection and medical photography. The body was the site at which to find out the 'truth'. And whilst in the images from Duchenne

and Curschmann we can see the disease represented within the body we do not 'see' the disease itself. The physical body presents with the disease; the symptoms of the disease can be read and traced in the body, yet the cause remains invisible to the eye. This changed however with the production of *Photo 51*, by Rosalind Franklin (1920 – 1958) as this is the image from which the structure of the DNA molecule was deduced. The image was taken by Franklin in the Biophysics Department of Kings College, London in 1952 using the process of Crystallography to produce an X-ray diffraction pattern.

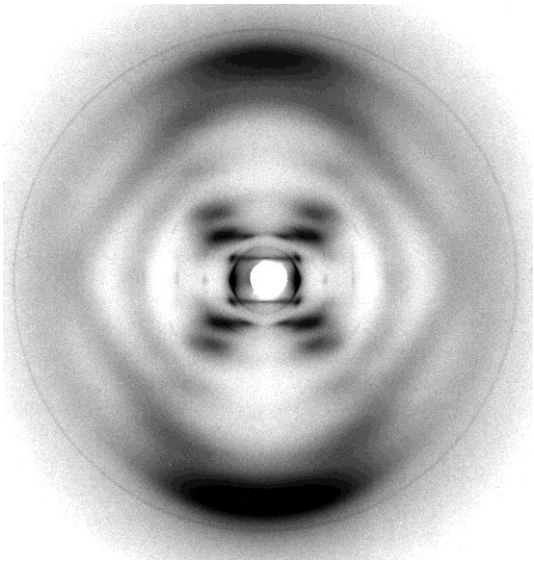

Figure 7 *Photo 51* (1952) Wellcome Library, London

In essence the image is that of the 'shadow' of the molecule that was captured by using a complicated x-ray technique with a high level of skill being required to interpret the image itself. Whilst an image of something is clearly visible to the naked eye on this photograph as Hacking points out, 'the reality in which we believe is only a photograph of what came out of the microscope, not any credible real tiny thing' (Hacking, 1983: p.186). So how can we begin to interpret the invisible in order to make sense of what is being visualised? Since the invention of the first type of microscope, circa 1590, very small and/or things that are invisible to the naked eye have become increasingly more visible and therefore the means to interpret these types of visualisation has been required. When discussing

the work *Micrographia (1665)* by Robert Hooke, Martin Kemp suggests 'continued challenges to our perceptual abilities' and that the key to how we 'see' the unfamiliar through the microscope is to be 'able to translate the seen patterns of lights and darks into a coherent, three-dimensional image with reference to known forms' (Kemp, 2000: p.42).

In the instance of *Photo 51*, the scientists, Watson and Crick, were able to 'translate' the pattern of light and shadow that the image produced and to construct the three dimensional shape of the molecule. However the interpretation of what we are actually seeing is not always so clear and/or possible to recognise or understand. Evelyn Fox Keller discusses the 'technologies developed in biology for peering into the secrets of life', and uses the term the 'biological gaze' to question, 'what can one see through the microscope? The question arises is it a real thing one sees? Is it an object on the slide or a spot on the lens?' (Fox Keller, 1996: p.111).

Robert Hooke noted how 'exceedingly difficult' it often is to distinguish between the real properties of an object and the artefacts of microscopic viewing'. (Fox Keller, 1996: p.111) And Gustav Bergman argues that:

> Microscopic objects are not physical things in a literal sense, but merely by courtesy of language and a pictorial imagination…When I look through a microscope, all I see is a patch of color [sic] which creeps through the field like a shadow over a wall.' (Bergman, 1943, cited in Hacking, 1983: p.188)

Visualisations of physical disease and in this context, genetic diseases, have become removed from the human form. The image of the physical 'self' is commonly visualised through DNA patterns (fingerprints) that resemble barcodes and the majority of media representation of genetic disease treatments and 'breakthroughs' is accompanied by an image made up of a graphic of the double helix structure, a DNA fingerprint image or a lab generated image of a cell type structure. The 'reading frame' has shifted and moved away from the graphically present manifestation of disease in the physical body that is captured in the medical photograph, and become a more sanitised and removed form of

visualisation. Whilst this ‘shift’ has had a ‘profound effect on our ability to visualise our inner bodies’ (Lupton, 2003: p.76) it also could be argued that it has led to ‘…an expectation that there is an expert solution to all of life’s problems’ (Lupton, 2003: p.76).

It is now genetic identity that is compared and contrasted and ‘looked’ at to ‘see’ what an individual is and more pertinently what may therefore be ‘wrong’ with an individual. If Joseph Sarrazin were to be diagnosed today his medical ‘portrait’, the image of the disease itself, would be rather different from the photographic image recorded in the clinic of Duchenne de Boulogne. The ‘portrait’ of Joseph Sarrazin would now comprise of an image that would appear on a Western blot. Western blotting is a technique used to detect proteins in a small tissue sample by homogenizing the tissue, separating the protein mix in an electric field and finally labeling proteins that have been transferred onto a membrane with highly specific antibodies. In a laboratory environment tissue samples are used from patients to gain a visualisation of what is in essence not visible. The Western blot consists of a number of lanes, with each lane representing a different tissue sample; there can be a number of tissue samples from different individuals on a single blot. There is always a ‘control’, a ‘normal’ readout of what is being examined and therefore by a process of comparison it is possible, through looking at the pattern labeled protein ‘bands’ to ascertain the presence or absence and the strength of certain proteins that are expressed within an individual tissue sample.

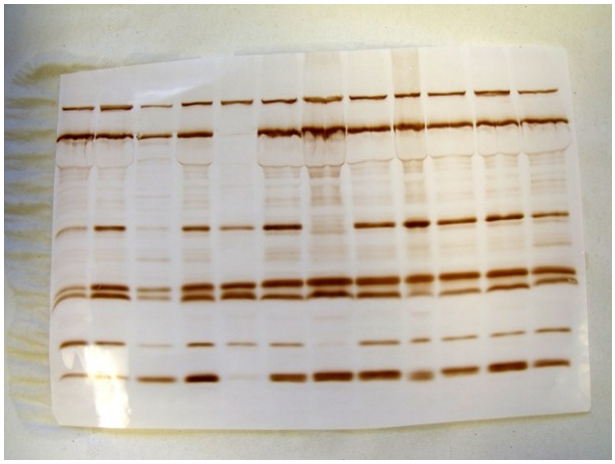

Figure 8 *Western blot*

The ‘read out’ for a patient such as Joseph Sarrazin would be likely to have a missing band that represents the lack of dystrophin, therefore a diagnosis would be made that the ‘weakness in the muscles’ that was presented to Duchenne de Boulogne was caused by a gene mutation that causes what is now called Duchenne muscular dystrophy. The Western blot is a reading, a ‘read out’ of an individual’s code, which can be read just as the physical body can be read for signs of disease. The laboratory ‘image’ of the body, of the patient, is now the ‘physical result’, the clinician can see not just what is ‘written’ but also ‘how it is written’.

3.5 Meaning: What we see

There are, however, differences in representation between the medical photograph and the diagnostic Western blot. Both images are essentially ‘showing’ the presence of a disease; the ‘intention’ of the images is therefore the same. How the images are read is not the same, as in reality the photograph, which would seem to ‘show’ more in fact ‘shows’ less in terms of a diagnosis. In the photograph we see the manifestation of the disease on the physical body and in the Western blot we see the absence of the protein that causes the disease. In the photograph we see the human form and therefore the ‘personess’ of the patient, the boy is a reality in the story of the disease. In the blot we see what is missing.

In order to attempt to construct an understanding of something that is not understandable by visualisation alone the use of comparison and ‘blending’ can lead to a more ‘readable’ whole. This process ‘the transformation of material into metaphor by cutting and pasting is a procedure familiarly known as collage’ (Anker, 1996: p.371). In linguistic metaphor one thing is used to describe another as with the commonly used genetic metaphor that DNA is like a ‘book’ and so can be read.

In terms of the photographic image and the image of the Western blot if these two images are put together through the 'artistic' means of cutting and pasting then is a 'new' or 'different' meaning created? Anker argues that in the context of what she terms as genetic art:

> …aspects of one image are substituted and reconfigured as part of another…The collage device, like film editing joins disparate elements in space and time and in doing so seemingly fuses fact with fiction. (Anker, 1996: p.371)

The use of collage was used as a research method in the studio, combining the historic photographic images from the clinic of Duchenne de Boulogne with the image of a Western blot, the two visual images blending in a collage type effect. The materials used, in this case agar gels and the cyanotype method of image making emulate the materials that are used in the diagnostic lab. The cyanotype method, the original 'blueprint', is a linear extension of the blueprint metaphor often used to describe DNA. The fragility of the agar and the destruction of the artworks overtime through 'wasting away' and disintegration either through chemical change or exposure to UV light is a straightforward 'cut and paste' of the progression of the physical disease. By the portrayal of the 'portraitness' of the Western blot the work seeks to compare and combine two things to make whole. Through their very nature metaphors 'turn' one thing into another, to change something, to metamorphosis the Western blot, which is a 'reading' of a disease with the absence of the body, back into a recognisable human form:

> …each human being has, in a sense, two bodies: an *individual* body-self (both physical and psychological) which is acquired at birth, and also the *social* body that it needs in order to live within a particular society. (Macnaughton, 2008: p.80)

Visualisations of disease in this context are created using a range of medium from the laboratory to the artist's studio and the photographer's lens. Advancing technologies have of course impacted widely on our ability to 'see' that which we once could not see. Whereas historically the disease was depicted on and in the physical body, increasingly

the disease is ‘seen’ outside of and away from the physical body. The diseased body has become absent in the depictions of laboratory diagnostics where once the body was always present in clinics such as those of Duchenne and Curschmann. The narratives that emerge from these types of visualisations are complex and at times ambiguous; *Photo 51* is the image of a shadow and it is somewhere within the molecule that is casting this shadow that the missing component, that causes the disease Duchenne muscular dystrophy, is not located.

4 *Saying*: The linguistic imaginings of disease

> ...metaphor is one of thought's most essential tools. It illuminates what would otherwise be totally obscure. But the illumination is sometimes so bright that it dazzles instead of revealing.' (Gray, 1991: p.485)

4.1 Introduction

This chapter will explore the linguistic elements of how, in the context of this investigation, we '*say*' the disease and the relationship between the language, the 'word', and the imagined 'picture' that the language creates. In the context of complex genetic diseases, attempting to *imagine* medical diagnosis and scientific explanations as familiar objects and or narratives through metaphor and analogy is a method often used to communicate across intellectual and emotional borders. If, as Ogborn suggests, 'the story involves unfamiliar objects which do unfamiliar things in an inaccessible world' (Ogborn, 1996) then the 'story' of the unfamiliar and the inaccessible must be told in a familiar and accessible way in order to aid understanding and comprehension.

To a non–scientist, the information that emanates from these disciplines is complex and often incomprehensible as the language used to define/explain/describe and ultimately to narrate what is going on can be unfamiliar. It is necessary therefore to use linguistic tropes in order to aid the comprehension of complex ideas. It is the use of this type of language that is examined in this chapter both in an historical context and also in the circumstances of the TREAT-NMD Network as used to explain complex genetic conditions.

The use of language to '*say*' disease in the context of this investigation is not concerned with the field of what is commonly known as 'narrative medicine' that is often considered in the medical humanities, Rita Charon argues:

> The effective practice of medicine requires narrative competence, that is, the ability to acknowledge, absorb, interpret, and act on the stories and plights of others. Medicine practiced with narrative competence, called narrative medicine, is proposed as a model for humane and effective medical practice. (Charon, 2006: p.33)

Narrative based medicine is widely documented as being a more 'holistic' approach and 'has arisen in counterpoint to…evidence based medicine' (Gwyn, 2002: p.143). This research, whilst acknowledging the existence of Narrative Medicine is concerned with the specific words and language that are used to describe difficult genetic concepts. Therefore the use and construction of metaphor and analogy to form a narrative rather than the act of storytelling and narration that is discussed in Narrative Medicine by writers such as Rita Charon in *Honoring the Stories of Illness* (2006) and Arthur Frank in *The wounded storyteller (1995).*

The use of metaphorical explanations in the context of this research is commonplace; however through creating these imagined fictions, the facts can become disturbed and or distorted. In *Illness as Metaphor (1991)* Susan Sontag advocated that 'the most truthful way of regarding illness – and the healthiest way of being ill – is one most purified of, most resistant to, metaphoric thinking' (Sontag, 1991: p.3). How then can we create a visual language for the 'unseen' that allows a better understanding in the world of scientific fact?

This chapter focuses on 'The Book of Life' analogy as a means to explain and navigate this complex field of study. At the same time, it also looks at how this analogy has been used and debated since it was first announced by Eric Lander of the Sanger Institute in 2000 that 'we just found the world's greatest history book' (Lander, 2000, cited in Roof, 2007: p.70). The aim is to consider how this analogy has become so embedded in the language associated with the Human Genome that it, along with similar analogies, has become fundamental to the interpretation and therefore the actual meaning of what they are describing and can therefore go unchallenged.

The ‘book’ that Lander refers to is one of many metaphorical terms used to try to explain the ‘secret of life’, the term coined by Francis Crick in 1953 when he and James Watson announced that they had discovered the structure of the DNA molecule. Some other commonly used terms are: blueprint, bar code, recipe book, map, fingerprint, computer programme, software and even ‘Chicago gangsters in a genetic landscape’ (Dawkins, 1989: p.2). Much is written about our struggles to find suitable and understandable interpretations of such things as DNA and in her book Science as Salvation Mary Midgley, arguing for clarity in the communication of highly technical disciplines, states that:

> …as in the Tower of Babel, each discipline speaks only in its own tongue. There is no interdisciplinary language for discussing the relations of studies to one another, nor to the world around them. Least of all is there any such language for considering the general meaning for us of each study, the part that it plays in life. (Midgley, 1992: p.2)

Without the language to explain this ‘thing’ that is invisible to us, we must find other ways to communicate. For how can we make a ‘*thing’* that we cannot *see* into something that we can *say*? Or, conversely, how can we make a ‘*thing’* that we cannot *say* into something that we can *see*? How can we interpret the story that the body is writing?

4.2 Metaphor

In this thesis the term metaphor has been used in a general way. The dictionary definition is defined as, ‘a figure of speech by which a thing is spoken of as being that which it only resembles’ (Chambers, 1998) and as Burke suggests, ‘metaphor is a device for seeing something in terms of something else’ (Burke, 1945, cited in Cameron, 1999: p.3). Complex and inhabiting a vast field of study, metaphor has been described as ‘a central tool of our cognitive apparatus’ (Cameron and Low, 1999: p.10). Although the Aristolian concept of metaphor, as written in the *Poetics,* is still fundamental to contemporary definitions, subsequent writers have argued that Aristotle ‘undervalued’ metaphor and saw

it as ‘merely an ornamental extra to language‘ (Mahon, 1999: p.69). As Lynne Cameron proposed:

> A general type of description of metaphor often seems to be the only level at which theorists and researchers of different persuasions can agree with similar ‘definitions’ found in many key publications (Kittay,1987; Black, 1979; Gibbs, 1994; Lakoff & Johnson, 1980). Once past this level of generality, disagreement develops in a mire of conglomerated detail, and intending researchers may find themselves reeling as they approach the published literature in order to select an appropriate theoretical and analytic framework for a study. (Cameron, 1999: p.3)

The impetus for this research was not to apply any particular theoretical approach to the use of metaphor within the field of investigation, but rather, to consider the use of such language within the context of the project and the TREAT-NMD network. Metaphorical language used by the network participants has been gathered and responded to in a creative environment that impacts on the practice-based research methodologies that have been used for this study. Metaphor itself, as argued in the pioneering work of Lakoff & Johnson:

> ... is pervasive in everyday life, not just in language but in thought and action. Our ordinary conceptual system, in terms of which we both think and act, is fundamentally metaphorical in nature. (Lakoff and Johnson, 1980: p.3)

This study therefore acknowledges the fact that the use of metaphor, as put forward by Lakoff & Johnson (1980), is ‘fundamental’ to our communication’.

Metaphor and analogy are two terms that are often interchanged and or confused in their usage as both terms are pertaining to the relationship between two things. Just as metaphor is defined as ‘a thing is spoken of as being that which it only resembles’ (Chambers, 1998) analogy is ‘ a similarity between like features of two things on which a comparison may be based’ (Chambers, 1998). The etymology of both words is Greek; metaphor meaning to transfer and analogy from the Greek *analogia* which means proportion (Mabelle, 2012). Thus metaphor transfers the meaning of one thing to another

whilst analogy gives the parallel relationship of two things – it is a comparison that points out and gives proportional relations to things or words. Both metaphor and simile are therefore forms of analogy (Mabelle, 2012). For the purposes of this thesis the terms metaphor and analogy are used to include other similar linguistic tropes such as, simile, metonym and synecdoche.

4.3 Metaphor and Disease

> Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. (Sontag, 1991: p.3)

Susan Sontag, with her two essays *Illness as Metaphor* (1977) and *Aids and its Metaphors* (1988), is the writer most commonly associated with metaphor and illness. As Clow argued:

> Sontag's book, *Illness as Metaphor*, has framed our understanding of the relationship between disease metaphors and illness experiences in modern Western society. (Clow, 2001: p.292)

The main thrust of Sontag's argument is that:

> ... illness is not a metaphor, and that the most truthful way of regarding illness – and the healthiest way of being ill – is one most purified of, most resistant to, metaphoric thinking. (Sontag, 1991: p.3)

Sontag goes on to argue that the metaphoric representations of disease (in her case cancer) can 'render diseases socially as well as physically mortifying' and that cancer sufferers are 'shamed and silenced by metaphors' (Clow, 2001: p.297). She also describes the metaphors used as 'lurid' and argues for 'liberation' from them (Sontag,

1991). The usage of the 'War Metaphor' is very common in the discourse of illness and disease; from the Edwardian period onwards (Lupton, 2003: p.62) the 'war against germs' is promoted and the use of such metaphors continues as society wages 'war' against the illnesses and diseases that 'invade' us. However as Lupton argues:

> There is a reflexive relationship between metaphorical discourse applied to illness and disease: just as other concepts or things are used to describe disease, so is disease used as a metaphor...for example disease metaphors are most commonly used to describe disorder, chaos or corruption, as when describing communism as 'a cancer on society' or describing a psychopathic murderer as 'sick'. (Lupton, 2003: p.59)

One of the focuses for this research is the metaphorical language used to describe and explain muscular dystrophies in particular Duchenne muscular dystrophy. As described earlier, this disease is caused by 'mistakes' in a gene on the X chromosome that is responsible for the production of the protein dystrophin. As this 'mistake' is part of the DNA in all cells of an affected patient the disease does not 'invade' or get 'caught' but it is intrinsic to the genetic make-up of the individual. The language used therefore to explain this type of mutation is not like the war metaphors that have been ascribed to conditions like cancer but are words that convey the idea of a mutation, 'mistake' or 'error', 'flaw', 'deletion', 'defect' and 'typo'. All of these words bring with them the individual definition of the word, for example the dictionary definition of 'flaw' is 'a feature that mars the perfection of something' (Chambers, 1998). There can also be multiple meanings for individual words dependent upon the context in which the words are applied. Lupton describes the word 'invalid' as being suggestive of 'a loss of integrity' (Lupton, 2003: p.59).

> In English, we use the same word to describe an expired passport, an indefensible argument, an illegitimate legal document, and a person disabled by disease. We call each of them *invalid.* To be an *invalid*, then, is to be an invalidated person, a human being stamped *not valid* by the invisible but invincible hand of public opinion. (Lupton, 2003: p.59)

The use of the term ‘invalid’ permeates the Andrew Niccol motion picture *Gattaca (1997)* in which the main protagonist, Vincent Freeman, is assessed genetically at birth for any weakness or defect and individuals are then categorised according to their genetic worth. In the film, Vincent is categorised as an ‘*in-valid’* or ‘*de-gene-erate’* as his genetic code contains a number of physical imperfections such as myopia and cardiac arrhythmias, he assumes the identity of a superior man in order to pursue his lifelong dream of space travel.

Films like *Gattaca,* Ridley Scott’s *Blade Runner* (1982) and the *X –Men* movies series (2000), all explore the implications of modern genetics and biotechnologies exploring themes such as genetic engineering, cloning, and mutation. For Vincent Freeman in *Gattaca* his labelling as an ‘in-valid’ is intrinsic to his genetic make-up, a genetically inferior man, Vincent is one of the last ‘natural’ babies born into a sterile, genetically-enhanced world, where life expectancy and disease likelihood are ascertained at birth by reading an individual’s genetic makeup. Vincent has not been ‘invaded’ by a disease or illness but is born with ‘weaknesses’ and ‘errors’ within his genetic code. This theme of a mutation is explored more firmly in the *X-Men Series* as within the society that exits in this fictional future there is a fear of the mutated humans by the general society of ‘normal’ humans. Whilst the language used in these examples is that of something *other*, the *mutant* and the *in-valid*, in all three examples the characters appear physically ‘normal’ – the difference or *other* is hidden from view and therefore invisible. In literature there are many references to genetic science and fictions that explore the themes of genetic fear and change that can/could pervade western societies and cultures. These works range from the idea of the ‘monster’ as in Mary Shelley’s *Frankenstein* written in 1818 *(Shelley, 2008)*, to creating clones to donate organs to save the lives of those afflicted by disease as in *Never let Me Go* by Kazuo Ishiguro (Ishiguro, 2005). The book *Mutant: on the form, varieties and errors of the human body* (Leroi and Tucker, 2005) considers the various representations of the mutant form as it has evolved through our genetic history. These portrayals of genetic themes within our contemporary culture and the use of visual and

linguistic metaphors within these films and literature demonstrate that just as the 'war' metaphor has been culturally prevalent in relation to illness and disease the metaphors for mutation and the identification of disease within an individual's genetic code can be seen to be pervasive since what has been termed as the 'genetic revolution'.

The 'unfamiliarity' and 'inaccessibility' of trying to make the invisible visible has been documented historically with Robert Hooke (1635 - 1703) the 'father' of microscopy who had to rely 'repeatedly on the use of analogies with the world of familiar objects' (Kemp, 2000: p.43). Hooke himself was 'dedicated above all to plainness and soundness of observation' (Kemp, 2000: p.43) and whilst Hooke's ability to illustrate what he was seeing under the microscope was incredibly accomplished it became more difficult when trying to explain using language, something that had never been seen before. It is Hooke who is attributed with the 'naming' of cells whilst observing thin slices of cork under the microscope. In "Observation XVIII" of the *Micrographia*, (1665) he wrote:

> . . . I could exceedingly plainly perceive it to be all perforated and porous, much like a Honey-comb, but that the pores of it were not regular. . . . These pores or cells . . . were indeed the first *microscopical* pores I ever saw, and perhaps, that were ever seen, for I had not met with any Writer or Person, that had made any mention of them before this... (Gunther, 1937)

It is said that the box like cells of cork reminded him of the cells of a monastery. Hooke compared the microscopic image that he saw of the structure of cork to something that was already familiar – the 'honeycomb or the 'monastic cell'. He did not have available to him a group of words that referred to this image because it had never been seen before. The word 'cell' now represents to us the 'thing' that is a cell, the unit that makes us. Our understanding of complex genetic conditions such as Duchenne muscular dystrophy is therefore constructed around the language that is ascribed to the explanation by the scientists, researchers and clinicians who research and diagnose such diseases and as Lupton points out:

> The frequent use of metaphor in the medical context is not surprising, for metaphor is used in all areas of verbal communication as an epistemological device, serving to conceptualise the world, define notions of reality and construct subjectivity. (Lupton, 2003: p.59)

4.4 The Book of Life

The production of a 'working draft' of the human genome was announced on June 26th 2000 with this 'breakthrough' being hailed as the 'Holy Grail' of genetic science. (Nerlich *et al*., 2002) In her book *The poetics of DNA*, Judith Roof, suggests that:

> The three acronymic letters then, like the chemical itself, have come to signify a vast number of processes undifferentiated to the non-scientist and rendered intelligible by a series of metaphors or comparisons. (Roof, 2007: p.7)

There are many analogies and metaphors that are associated with DNA such as the 'secret of life', the code, the book, the alphabet, the Rosetta stone, the Holy Grail, the recipe, the blueprint, the text, the map and as Roof also points out:

> None of these analogies is accurate in terms of how DNA works or even what it accomplishes. All of them import values, meanings and mechanisms and possibilities that are not at all a part of DNA. The effect is that DNA has always stood for much more than what it is. (Roof, 2007: p.7)

Nerlich *et al* have completed a piece of research titled '*The Book of Life: how the announcement of the completion of the Human Genome Project was revealed to the public'* (Nerlich *et al*., 2002). Whilst the impetus and context for Nerlich's research is not of particular relevance to this practice based project, the study does highlight many of the issues that form the context in which this investigation operates. Whilst the work of Nerlich *et al*, in this instance, examines the portrayal and use of language by the press and media, for the purposes of this research it is relevant that the 'book' metaphor has many diverse connotations. References including those of Christian religion, 'pagan echoes' of

the Egyptian '*Book of the Dead',* and on examining the language used by President Bill Clinton at the Press announcement of the completion of the Human Genome Project Nerlich observes that:

> The book metaphor also links with Clinton's reference to Galileo, who had described the universe as a great book written in the language of mathematics. Many 17th century scientists, such as Francis Bacon, followed in trying to sell the scientific revolution by urging their audience to learn to read both the Holy Book and the Book of Nature. (Nerlich *et al*., 2002: p.451)

The paper published by Nerlich also includes the diagram below, denoting the links to the many interpretations that have been ascribed to the 'Book of Life' analogy.

Table 1 The Book of Life

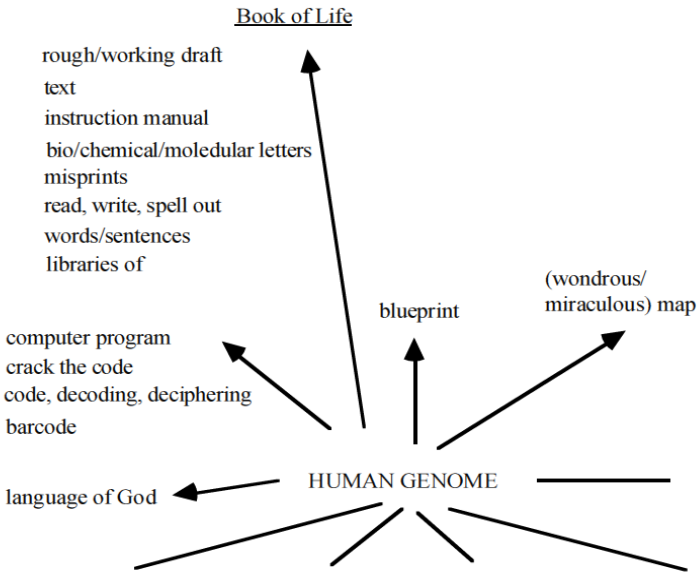

Figure 1 **Metaphors and comparisons used to describe the human genome.**

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(Nerlich *et al*., 2002: p.456)

To explain a disease diagnosis to a patient involves the use of metaphor and analogy to describe and clarify the underlying genetic processes that have taken place. To various audiences and recipients, each rendering of the order of words and the 'pictures' and

associations that these words evoke has enormous potential for change and interpretation. As Van Dijck points out:

> The concept of a gene or a molecular structure is a very difficult concept to convey, and for its public understanding, scientists have to rely on representational analogies. Models and metaphors provide recourse to analogy when words fail; they resemble each other in the sense that they both introduce new meanings, and transfer a construct from one domain to another. (Dijck, 1998: p.22)

Some metaphorical explanations of the DNA and the processes that occur within the transcription of the DNA can appear quite simple:

> The genome is a book...with 23 chapters called chromosomes, where each chromosome contains several thousand stories called genes, where each story is made up of paragraphs called exons which are interrupted by advertisements called introns and every paragraph is made up of words called codons and each word is written in letters called bases. (Ridley, 1999: p.6)

Ridley's description of the genome as a book interchanges individual words with others thus making unfamiliar words become familiar; a *chromosome* becomes a *chapter* and a *codon* becomes a *word* and so on. The table below produced by Nerlich *et al* records the words used in the field of Biology and then the word that is used as a 'replacement' in genetic discourse.

Table 2 Language relating to genetic discourse

Table 3 **Language-related metonymies and metaphors used in genetic discourse**

Biology	*Language*
base (e.g. thymine = T)	letter
four-base group	word
gene	sentence
chromosome	chapter
DNA	language
genome	'The Book' (of Life)

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(Nerlich *et al.*, 2002: p.460)

However as Van Dijck argues the use of these types of word transfer are not always conducive to real understanding:

> To compare a gene to a video tape and the genome to a video recorder for instance consciously transfers the everyday language of video technology onto a complex scientific concept which at least gives the lay audience the illusion that they understand the basic mechanism of genetics. (Dijck, 1998: p.22)

There are also examples where the linguistic process and the application of language can lead to a complicated and difficult explanation even though the impetus for which is to make the information more accessible:

> I shall make use of the metaphor of the architect's plans, freely mixing the language of the metaphor with the language of the real thing. 'Volume' will be used interchangeably with chromosome. 'Page' will provisionally be used interchangeably with gene, although the division between genes is less clear than the division between the pages of a book. This metaphor will take us quite a long way. When it finally breaks down I shall introduce other metaphors. Incidentally, there is of course no 'architect'. The DNA instructions have been assembled by natural selection. (Dawkins, 1989: p.22)

The above explanation from Richard Dawkins a popular writer and scientist, attempts to convey some of the complexity of the subject in an accessible manner. This example is an explanation within an explanation, as Dawkins uses caveats to talk the reader through how certain words and language will be used. Whilst this linguistic 'turn of phrase' may be easier for some to grasp, it can still fundamentally be unclear. It can be argued that the use of these types of metaphor, even though sometimes complex in themselves, can actually lead to what is fundamentally simplicity of understanding that is not altogether true. As Roof points out (in the context of Cystic Fibrosis):

> …the concept of gene therapy for example, imagines the insertion of either the proper or corrective gene in place of genes that are damaged… The idea is that doctors simply rewrite the bad script and, if imagined through the metaphor of the text, this indeed seems like a simple task. (Roof, 2007: p.160)

The implication here is that the task of 'rewriting' the 'bad script' is simple when in fact it is not. Michel Morange argues that the use of some metaphors to describe what genes actually do (his example is that of gene action on behaviour) 'is only an elegant way of hiding our ignorance' (Morange, 2001: p.52). And that genetics are far more complex than statements such as 'We have discovered the human alphabet - what we now have to do is put the letters in the right order and make a sentence (Toy, 2000, cited in Roof, 2007: p.84). As Eric Lander commented after the completion of the Human Genome announcement:

> In June maybe people thought we had this big pile of letters and it was all stuff. But I don't know if people realise that we just found the world's greatest history book. We are going to be up every night reading tales from the genome. (Llander, 2000, cited in Roof, 2007: p.84)

The Human Genome - 'The Book of Life' contains, as Francis Crick announced in 1953, the 'secret of life'. However, Judith Roof suggests that the 'story' within the 'book' does not quite fulfil the expectation. For whilst it may at first have seemed to be 'the answer to everything' (Roof, 2007: p.70):

> At the same time we are queasy about something... Just as DNA's matching pairs make it able to reproduce itself; our representations of DNA somehow reproduce ourselves – our anxieties, contexts, and ways of thinking. (Roof, 2007: p.70)

For as Nelkin comments:

> The gene is a biological structure, the unit of heredity, a sequence of DNA carrying the information that helps to form living cells. It is, in its biological reality, text without context, data without dimension. But the gene has also become a cultural icon, a convenient way to explore the essence of identity, and the forces that shape human nature. (Nelkin and Anker, 1996: p.56)

This biological structure can be 'seen' as a portrait, a 'picture' of us as individuals, it contains all of the information required to make us into formed human beings. We know that it has a shape and this shape is the Double Helix structure. We '*say*' the biological

structure as a ‘code’, a ‘book’, a text that can therefore be read, and a recipe that can be followed and unravelled. As discussed, communications of this type are widely debated and are constantly being developed by scientists, writers, artists and the general public. Words like ‘code’, ‘recipe’, ‘text’ immediately imply that all of the associated actions attached to these ‘things’ can be carried out in the context of understanding how the human genome works and is put together. We can *decipher* a code, *follow* a recipe and *read* a text.

An article in the *Observer (2008)* compiled a simple list in an article entitled *What DNA can tell us* beginning with gender, hair and eye colour, how the body clock works, thrill seeking, obesity, forensics and disease. Whilst at first glance a simple list, it contains incredible detail about the scientific specifics and statistical information. Attention deficit hyperactivity disorder (ADHD) ‘has been linked with a genetic stutter in the gene DAT1 which is involved in nerve impulses’ and ‘Up to 80% of women with the BRCA1 or BRCA2 genes will develop breast cancer’. With regards to obesity:

> Around half of the UK population carry a variant of the FTO gene, which makes them on average 1.6kg heavier than those who do not have it. Some 16% of the population carry two copies of the sequence variant and are, on average, 3kg heavier. People with the FTO variant also have an increased risk of diabetes. (Randerson, 2008)

This sort of data that mixes a simple list with complex scientific information is readily available. We all, no matter what our age, race, gender, background or intellectual ability have access to this sort of information, and whilst we may not understand directly what a BRCA1 gene mutation or an FTO sequence variant is, we will certainly have a perception of what it is and may wonder if we ourselves ‘have’ one. This type of statistical and gene ‘naming’ information available in the popular press can then be combined with what we know or have heard of the genetic metaphor as Gwyn argues:

> We get to know about our own illnesses through the language of doctors and nurses, friends and relatives, and we often recycle the words picked up from our consultations in the doctors’ surgery into conversation sprinkling our stories of

> sickness with epithets that give an impression of a grander knowledge of medical science. (Gwyn, 2002: p.6)

This could hypothetically lead us to wonder as Roof does that 'If genes are books and DNA is an alphabet, then what is to stop us from changing the story?' (Roof, 2007: p.60). There are those who argue that the use of metaphor and analogy in the context of genetic explanation is therefore inappropriate and simplified. Just as Sontag argued for a 'resistance' to 'metaphoric thinking' (Sontag, 1991) Michel Morange, in his outline of current conceptions of the gene argues:

> ...it is the very power of the metaphors that are linked to the concept of the gene that strikes fear into the hearts of those who worry about the direction of genetic research. (Morange, 2001: p.10)

Some argue that the use of metaphor in the context of genetics is inappropriate and over simplifies the complexity of the science with Mary Midgley commenting that:

> ...Why are these metaphors proving so helpful, so enormously convenient that some people do not notice they are metaphors at all? Such people innocently suppose that to say 'DNA contains the necessary information, is to say something as straightforward as that it contains the necessary carbon and hydrogen. (Midgley, 1992: p.12)

Whilst Esteal argues:

> Areas of biomedical research are being referred to as "genomic annotation..." The metaphor is usually lexigraphical: The genome is a dictionary filled with words whose meanings we are challenged to discover. Organisms are books, which we will be able to read once we understand the words. There is talk, in the context of model species, of "Rosetta Stones" and "Chaucerian English". This is a poor metaphor. We (I mean non-Russian speakers) can never hope to understand The Brothers Karamazov equipped only with an annotated English Russian Dictionary. (Esteal, 2000: p.1775)

The confusion that can be caused by the use of 'inappropriate' metaphors can be seen as so great that Nobel prize-winning biologist David Baltimore has suggested that DNA is 'a reality beyond metaphor' (Strauss, 2009: p.158).

A less radical view is held by those who argue that 'better' and more 'suitable' metaphors should be found:

> The problem...is that DNA is both potentiality and actuality. Yes, it is a blueprint, but a blueprint that in a certain way transforms itself into the building it is designing. It is a photocopier, photocopy and the original. (Strauss, 2009: p.154)

John Turney advocates that we require ways of 'framing, metaphors... which will help get the *story* written clearly and expeditiously' (Turney, 2009: p.136). Whilst others like Dennis Noble, suggest a change to this philosophy and to replace 'the book of life' metaphor with 'the music of life' and 'to lead scientists away from single genes to talk systems and interactions between elements of the system – think of gene organism interaction as polyphonic music' (Turney, 2009: p.137). Copland, in his article '*The Book of Life',* suggests that 'the mistake' was in thinking that 'the genome was itself the book of life', he argues that it would better be thought of as 'the dictionary to the language of life' (Copland, 2005: p.278). The varying discussions and arguments that exist around the use of linguistic metaphor and analogy in the context of DNA and the Genetic Code is succinctly concluded by Stephen Strauss who states, '...ultimately there is a science and there is a metaphor, but as far as I can tell, there is no science to a metaphor' (Strauss, 2009).

4.5 The Typo

The use of metaphor for scientific explanations, and in this context, explanations of disease is endemic and incontrovertible in its usage. Kemp argues that when using this type of metaphorical language, just as the visual carries the 'baggage of association' (Kemp, 2003), so the linguistic interpretation that can be construed from this type of

language can sometimes be misplaced. In order to address a genetic disease we first have to identify what causes the disease, the genetic mutation. In order to do this we have to be able to look at a person's genes. Seeing patients' genes from the scientist/clinician perspective and then translating and explaining this information to a patient is where the majority of the explanation type metaphors occur. If it is discovered that the cause of a genetic mutation is because something is missing then just like the Roof example for Cystic Fibrosis, it is easy to see that a 'lay person' could make the understandable assumption that it would therefore be quite simple to replace the bit that is missing and therefore fix the problem with the 'doctor rewriting the bad script' (Roof, 2007).

In the context of this investigation, the language used by Professor Volker Straub to explain the genetic diagnosis of Duchenne muscular dystrophy to a patient is that of the 'book'. The text below was provided by Professor Straub when asked to recount how he would explain a genetic diagnosis to the family of a patient in his clinic:

> 'A gene is like a construction plan (recipe) that informs the cell how to make a substance (protein) that is relevant for the cells function. The gene or construction plan for dystrophin, the protein that is missing in muscle cells from patients with Duchenne muscular dystrophy, is very large. It's a construction plan consisting of about 2.5 million letters. We have 3 billion letters that make up our DNA and finding the genetic change, which we call a mutation that causes Duchenne muscular dystrophy, can be like looking for a typo in one of these 2.5 million letters. Because the construction plan for the dystrophin protein is so big, it can really be compared with a big book, e.g. the New York telephone directory, and you have to find the typo in it. Once you find the typo, you then still need to prove that it is really responsible for the disease, which isn't necessarily the case, as all our genes or construction plans are slightly different, which is why we are all individual. We have more than 20,000 genes in all of our cells. The entirety of our hereditary information is called the genome, which one can almost compare with a library consisting of at least 20,000 different books. You can imagine that it can be very challenging to find a genetic change if you don't know where to look. It would be like looking for a typo in one of the books in this library'. (Straub, 2012)

This analogy uses the 'book' metaphor and conveys the enormity of the genome and the complexity of the task faced by the researcher/clinician by using terms such as 'library' and the comparison of a 'telephone directory'. The information held in a telephone directory is of course very similar page to page. There is also in this analogy the

introduction of ‘doubt’ as to where the researcher/ clinician should begin to ‘look’ for a ‘very small typo’. This analogy therefore conveys ‘volume’ of information, ‘doubt’ as to cause of a particular disease and reinforces the ‘individuality’ of each patient. It is beyond the scope of this thesis to consider the research that has looked at particular public and patient response to the use of this type explanation and language. However it does acknowledge that studies such as those by Nerlich (Nerlich *et al*., 2009) and Condit (Condit, 1999) add a dimension to this type of research that explores more fully patient reaction and response to the use of this type of language.

4.6 Language Lab

The Language Lab website (Wilde, 2009) was launched at the TREAT-NMD International conference in Brussels in November 2009. It was envisaged that the website could be used as a vehicle through which to ‘collect’ the metaphors and therefore the language that was being used by the TREAT-NMD network members. The website was announced in the TREAT-NMD newsletter (Appendix 7) with a quote from Professor Volker Straub:

> In a highly specialized [sic] and complex field like that of inherited muscle diseases, specialists tend to simplify complex facts related to genetic diagnosis, disease mechanisms and potential treatment strategies by using metaphors, analogies and models. Patients and families do the same thing when talking about their conditions. Based on our differing backgrounds we visualize and reflect on things in different ways and this project is exploring these processes by using art as a more general, non – linguistic concept. Particularly in a multinational, multilingual network like TREAT-NMD, this kind of project has the potential to give us new insights into ways of explaining the disease we deal with every day. (TREAT-NMD, 2007)

In order to begin the ‘Metaphor Collection’ (Appendix 8) a form was distributed at the International Conference in Brussels by this researcher. Three example analogies, suggested by TREAT-NMD appeared on the form as follows:

> DNA is a knitting pattern for living things…

> If your DNA is a recipe book, a mutation is like a typo that causes you to make the wrong dish.
>
> Imagine you are a computer; the hardware is fine but the software needs some attention.

The original intention had been to collect examples of the metaphors and analogies used by the network members and to explore this language further through the artworks that were being created in the studio practice. At this stage in the project it was also envisaged that an archive would be created to collect the ‘language ‘of the TREAT-NMD network.

'Language Lab' was a vehicle that enabled a number of things to happen. The idea of the website was initiated by me after attending the Brussels Conference with TREAT-NMD. As will be discussed in Chapter 5, whilst I had initially wanted to take some form of physical artefact to the conference, to introduce the research project to members of the European Network, the *Vials Project* [Fig.13] had not yet been resolved. I therefore designed a method by which to collect the metaphors and analogies used within the network to describe the disease. It was intended at this time to use the 'language' collected within some of the works and to create an archive that would physically represent the disease metaphors in this context. A form was distributed at the conference for the metaphor collection and the website was launched in the TREAT-NMD newsletter. The website was also a vehicle to document the progression of the studio practice and to have a Gallery facility to disseminate the artworks and news and events that were linked to the project. Whilst reaction to the website from within the Network was mostly positive, the design and implementation of the site itself proved to be time consuming and difficult. Site traffic was relatively small and only received responses and 'metaphors' to collect when people were personally prompted (usually by Professor Straub) to do so. Whilst there has been a limited response to the site the responses that have been received have been very positive. The capacity with which to populate and disseminate information about the site has been challenging for one person to do (with some technical help

provided by TREAT-NMD). The site has proved successful in collecting some metaphors and has been a useful way of promoting the research project in terms of information dissemination. With sustained effort and by using existing methods of dissemination such as newsletters, web links and blogs, the Language Lab could become a much larger and separate piece of research.

The examples that were collected, (Appendix 9) whilst a small sample, show the type of language that is in use within the network of TREAT-NMD. The narratives that emerge are therefore indicative of the previous research showing that common comparisons are those of books, recipes, computer programs and plumbing. This research, in relation to the metaphors used, has taken a pragmatic and narrow approach in focusing on the specific words and sentences that are used in the context of 'explaining' difficult genetic diagnosis in particular to the non – scientist.

In her work *Illness as Metaphor* Sontag uses literature to demonstrate how the metaphorical use of language is pervasive throughout literary texts and how therefore the 'meaning' of the metaphor becomes the depiction of the disease. The metaphors that have emerged from this research would seem to conform to the commonly held comparisons of comparing biological systems like DNA to 'things' like books and VCR's or to a form of action, as in a method to fix something, as in plumbing:

> Treating MD right now is like working on plumbing. The drain is clogged, and at this time, all scientists can do is pour nuts and bolts down the drain. They know where the problem is, and how to get close, but cannot get more specific at this time.
>
> Chromosomes are like looking at the spine of a book. When we look at a child's (foetus') chromosomes it's like making sure all the books in the series are here. Genes are paragraphs in the book. Just by looking at the spine of the book, we can't tell if there is a typo on page 56. If we want to look for a typo (genetic disease) we have to know about what book and what page else we're likely never to find it.
>
> Imagined you have programmed your VCR to record a movie on TV: problem, there are a lot of ads (INTRONS). Your VCR is very clever and can stop recording at ad times so you can see the whole movie. Sometimes your VCR fails and forgets to tape a couple of the movie bits between ads (EXONS), if what is missing is not important (a silly car chase) it may not be relevant (Becker), if it is the scene where the evil guy is unmasked the rest of the movie may not make any sense

> (DMD). When Exon Skipping we deliberately delete a couple of the scenes (getting rid perhaps of a secondary character) to make a shorter movie but an understandable one... (Appendix 9)

As argued earlier, some metaphors can be seen as inappropriate and confusing and so therefore 'unsuccessful' if the purpose of them is to be that of explanation. As cited earlier from Van Dijck (1998), the use of this type of metaphorical language can create (for the lay-person) the 'illusion' of understanding something that is as complex as a genetic diagnosis as opposed to a real understanding.

The use of the word 'illusion' by Van Dijck is interesting as an illusion is 'something that deceives the senses or mind, e.g. by appearing to exist when it does not or appearing to be one thing when it is in fact another' (Chambers, 1998) and whilst in the context of scientific metaphor construction for explanation there is no evidence of a cognitive deceit, the idea of one thing appearing to be another is how a linguistic metaphor works. If we take the Aristolian view of l*ogic*, *rhetoric*, and *poetic* then the use of metaphorical language at all can be seen as misplaced in the sciences. As a subject area it would have 'clarity' (Hawkes, 1972: p.7) and purport more to the view of Robert Hooke (1665) for 'plainness and soundness of *Observation*' (Gunther, 1937). However, 'a good metaphor implies an intuitive grasp of dissimilars' (Evans, 2008: p.66).

In the case of a genetic mutation the word mutation has developed some negative association. A mutation:

> …a random change in a gene or chromosome resulting in a new trait or characteristic that can be inherited. Mutation can be a source of beneficial genetic variation, or it can be neutral or harmful in effect. (Chambers, 1998)

We effectively evolved through the process of genetic mutation (Leroi and Tucker, 2005) and yet the connotation attached to the word can suggest deformity, and strangeness. Indeed the Victorian Freak show had its roots in the strange but sometimes 'true' human

exhibits (Stephens, 2011). So whilst the word mutation means *to change* it has overtime developed an association which may well be our first thought when presented with the idea of it. So to be told that a disease is the effect of genetic mutation, whilst being literally true comes with all of the associations that are attached to this one word be they positive or negative. The metaphorical language can therefore be interpreted as 'clear' as in scientific, or 'illusionary' as in the more literary and poetic use of language. Susan Sontag (1991) used the evidential language of literary texts to argue her point that the use of such metaphorical language in the context of illness, 'create[d] diseases that have been spectacularly and similarly encumbered by the trappings of metaphor...' (Sontag, 1991: p.5).

The narrative structure of storytelling plays an important role in the ability for clinicians, researchers and patients to communicate with one another about illness and disease. In the context of complex genetic diseases, attempting to *imagine* medical diagnosis and scientific explanations as familiar objects and or narratives through metaphor and analogy is clearly a method often used to communicate across intellectual and emotional borders. It is clear from this research that the use of the 'book' metaphor is still very prevalent and is used actively within a medical, clinical environment. However it is also clear that these explanations are often encumbered with conventions that are attached to meaning, thus contributing to a more layered narrative.

5 Studio Practice as Research

5.1 Introduction

This chapter examines the completed artworks and the methods and materials of the studio practice that underpin the research project. The objective of the research was to use the methodologies of an arts practice to develop a series of creative works that were stimulated by, and that responded to, the visual and linguistic methods used by researchers, clinicians and patients to communicate the complexities of disease causing genetic mutations within the TREAT-NMD network. Whilst this collaboration was the starting point for the investigation, with a focus on the Muscular Dystrophies, the research activity ranged across the historic and contemporary fields of visual interpretation within the broad subject areas of art and medical science.

The relationships that have subsequently developed between the artist and the scientist, the art studio and the scientific laboratory, provide the context in which these artworks were created. These physical works aim to articulate a discourse between how we '*see*' and how we '*say*' what is, in essence, invisible. It is therefore important to establish a clear frame of reference as to how the creative research is carried out, and also to illustrate the historic context that has influenced the framing of the research methods employed.

Whilst this research is based on a collaborative relationship with the TREAT-NMD network and is therefore concerned with the visual and linguistic tropes associated with genetics, it is fundamental to the thesis that the primary site for artistic interpretation is the physical human body. It is on and within the physical body that the disease manifests itself and it is therefore the *story* that the physical body is writing that is being investigated in the artworks.

5.2 The Blank Canvas

My working experience as a visual artist is typically project based and context specific. In charting how the arts practice and therefore the research outputs came to function and be completed in the context of this research, it is important to note that at the outset whilst I imported my habitual working methods as a practitioner, there were no discernible artworks or studio methods that were actively brought to bear on this current research. However, past projects had resonated with the ideas of narrative structures both visual and linguistic, the value of absence and invisibility, and with the traces of memory that can create new narratives from the ‘blank’ or ‘absent. Glass and paper were the predominant materials used in previous works, often with a method of alteration taking place during the process of making through glass fusing and kiln techniques. In simple terms, on day one of the project there was an empty studio space with an artist who had an interest in language and absence and who often used paper and glass as materials, but in essence, the starting point for this project was a ‘blank canvas’.

Figure 9 Empty Studio (2009)

It was necessary at the outset of the project to develop strategies that enabled the research and studio making to begin. A number of lines of enquiry were developed

through meetings and establishing relationships within the TREAT-NMD Project Office, developing links and arranging visits to the research laboratories at the Institute of Genetic Medicine in Newcastle and through more traditional desk-based research.

5.3 Avenues of Research Inquiry

The following lines of inquiry began to emerge regarding the visual and linguistic depictions of the neuromuscular diseases that were of concern to the TREAT-NMD network.

1. The diagnosis of the diseases in question and the scientific methods and materials used to do this within the laboratory.
2. The historic progress of the disease and how over time advancing technologies have changed the visual interpretations of the disease.
3. The types of language and words used in the descriptions of and explanations of the disease itself.

Information around these emerging themes was gathered in a number of ways. Notes were made during meetings, photographs taken of laboratory tours and literature and images were collected through desk-based activity. As this information began to accumulate it was sorted into two broad categories. These categories were 'how we *see* the disease' and 'how we *say* the disease'. The 'seeing' of the disease included historic medical images, primarily medical portraits that were used for diagnosis, historic drawings by clinicians (see Curschmann, 1894; Duchenne, 1862; Gowers, 1879), laboratory diagnostics, graphics and more contemporary artworks that depicted, in their broadest form, the representation of genetics and genetic disease. The 'saying' of the disease, in particular the use of analogy and metaphor, comprised of historic writings of diagnostics by physicians such as Gower's and Duchenne, information for patients and practitioners

that was generated by the TREAT-NMD network, academic references to the history and contemporary attitudes to disease and the *Genetic Revolution*, writings about the discovery of DNA and therefore the impact of the discovery on diseases such as the muscular dystrophies, and the response by artists such as Anker, Borland, Kac and Quinn who choose to use genetic medicine as a field of investigation.

To begin the research process in the studio, appropriate methods to organise, select, analyse and to sort the resources to facilitate a meaningful influence on the artworks were required. As a collaborative project, the approach to the studio practice was very much modulated by this. Outcomes needed to be measurable, which is a different premise from the making of an artwork that grows from a purely creative and inspirational act. The artworks created as part of this research investigation were very much grounded within a contextual framework, as the practice itself was required to be articulated as a research output. At this stage in the project a process of immersion into the creative process took place and the studio became a physical area for creative investigation. The creative process itself and the contemplation of the created artefact became a method of working that was not necessarily driven by actively seeking a solution to a posed question, but more a method developing out of the myriad data that was collected. In essence the task was to develop and test a range of representational strategies that begin to address the research question. Through this type of activity and exploration there began a process of sifting through the resources and developing creative ideas until a work of some sort or test piece was produced. It began to emerge that the impetus for the work was very much focussed on the 'unfamiliarity' of ideas and materials and thus the working method within the studio began to resemble a testing ground with very little certainty as to the success and material stability of the creative outputs. The immersion of the practice in this way created a space in which to speculate on the complexity and unfamiliarity of the emerging landscape and for the struggle to make stable new materials and ideas valid.

5.4 The Research Data

The research data that was collected from the various interactions with 'people' (TREAT-NMD), 'places', (the laboratory) and 'things' (images and writing) fell into three avenues of inquiry; the history of the disease, the laboratory and the disease, and the language of the disease. A research method began to develop whereby the impetus for the creative works began to emerge from a narrative that was constructed through a combination of visual and linguistic information that emanated from the data that was being collected. At this early stage it became clear that my overwhelming response to the data was one of 'unfamiliarity' with the language, ideas and materials that were being discovered and used during my communication with the *people*, *places* and *things*. It was this unfamiliarity that gave rise to the initial visual map that was created in the studio in order to make some sense of any narrative that was beginning to emerge.

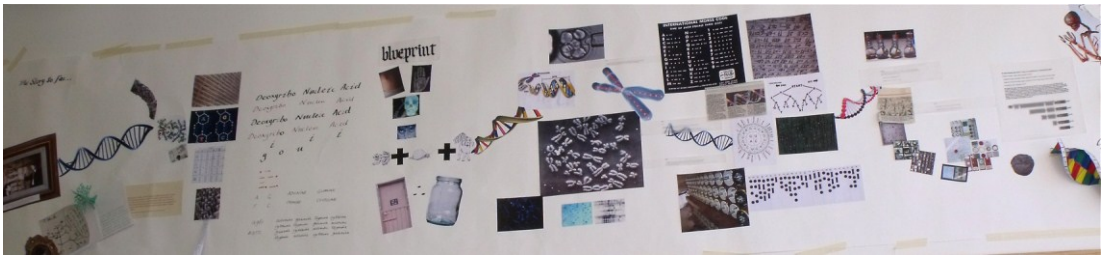

Figure 10 Studio 'map' of data (2009)

This working method can be evidenced from my notebook in which the initial steps and ideas for the creative works are recorded and from the photo archive of the studio work.[8] [Figs.38-48] The unfamiliarity that existed throughout the initial research time was not just with a strangeness of language but also with an inability to recognise physical 'things'. Many of the individual words used during meetings were unpronounceable by me and therefore any understanding gained was quickly lost, seeping away as the distance between the conversations grew. The materials and equipment used within the laboratory

[8] It is important to note here that discussing the approach above retrospectively does afford solidity to the method that was not so apparent at the outset of the project.

setting had a vernacular all of their own and therefore my visual interpretation of the information that was being considered in the initial research time translated into a visual map that was quite random in its structure. This map became a list of visual bullet points, an interpretation made up of collected images and texts that had a direct link, or were illustrative of, the research context. This visual map took as a starting point the evolutionary thesis put forward by Charles Darwin (1809 – 1882) and moved through the linear historic narrative of the discovery of the DNA molecule by Crick and Watson in 1953 through to more contemporary diagnostic and microscopic visualisations of the concept(s) of genetics. From this ‘start point’ images of other related ideas emerged such as those of codes and coded languages, common social and linguistic interpretations of genetics with the use of words such as ‘blueprint’ and common analogies such as ‘the book of life’.

The ‘missing’ gene (in the context of this research the dystrophin gene) as an idea resonated strongly with my previous arts practice that was concerned with the invisible and the frozen narratives that exist all around us. Whilst the concept of DNA transcribing and copying itself repeatedly gave rise to the comprehension of an ever mobile, but contained, archive of humanity that exists within each individual being.

The visual map began to give rise to these 'shadowy' ideas and thoughts that were concerned with ‘things’ that are missing and/or invisible, ‘things’ that are seen but are in essence invisible and ‘things’ that change from one thing to another. These initial ideas became more fully elucidated on arriving at the first image of any real significance that began to resonate with the practice, which was *Photo 51,* by Rosalind Franklin (1920–1958). This photograph, as well as having enormous historic significance, also depicts the conundrum of the posed research question of how we see that which is invisible. As whilst this photograph is the x- ray from which the shape of the double helix was deduced by Crick and Watson it is in reality a photograph of a shadow, the shadow of the molecule itself. And as Fox Keller points out the molecule itself would have been rendered “dead” (Fox Keller, 1996: p.108) by the very process of the image capture. *Photo 51* therefore

holds within it a number of the key elements from which the premise of how can we *see* something that we cannot *say* and how can we *say* something that we cannot *see* emerges.

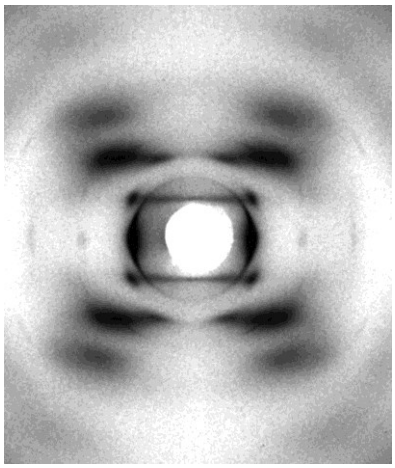

Figure 11 *Photo 51* detail (1952) Wellcome Library, London

Photo 51 presented to me the archetypal image; an image that captured the very essence of not only the molecule itself but all that came after, from the discovery of DNA, to questions about human essence, evolution, heredity and identity. It was from this image that the basis for the studio practice in this research context became formulated. The works being created, whilst embryonic, could clearly be defined as 'maps' of the data that had been combined in often random groups, which came largely out of an ignorance of the field that was being explored. So by literally not understanding much of the terminology and physicality of the world of science not only did a new landscape for the practice began to emerge, but I also began the process of developing appropriate mapping tools by which I could orientate my understanding of the field through my visual art practice.

5.5 Visual Depictions

Alongside the making of the visual ‘map’ or storyboard of collected ideas I began to make ‘visual depictions’ of some of the ideas and explanations that were emerging from the research. Whilst often crude in their form, it was an early attempt to develop the expressive resources so as to enable my sculptural interrogation of a language or description of ‘things’ that transpired from the data. The paper double helix is based on the shape of the DNA molecule as discovered by Crick and Watson and as captured in *Photo 51* by Rosalind Franklin. The making of these shapes in the studio allowed for a ‘hands on’ feel that gave a tangible form to the data. As identified earlier in this chapter, Franklin’s photograph is an image of a shadow from which the Double Helix shape was deduced and is therefore an illustration of how the molecule is constructed. During this making process I began to experiment with materials, moving away from the solidity of card and paper and making the helix shapes more fragile by cutting away the structure and using Japanese rice papers. Retrospectively, this shift in material was a way to demonstrate the vagueness that I was experiencing when attempting to ‘make’ any studio output. The material therefore came to represent not only fragility but also a lack of concrete understanding of what the ‘thing’, in this case the molecule, actually was.

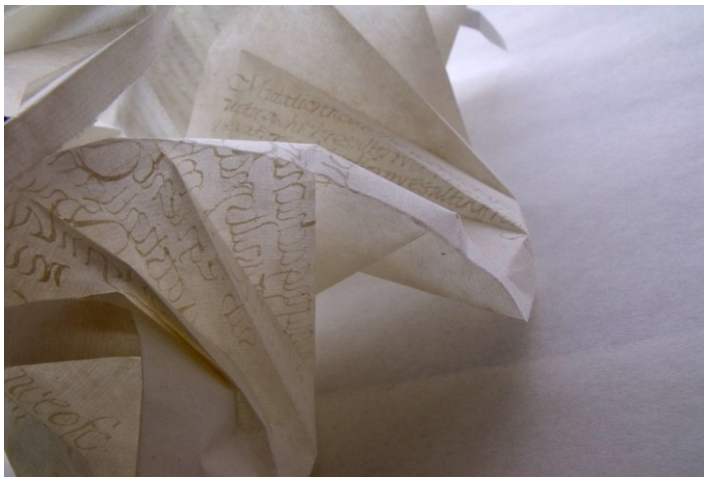

Figure 12 Paper Helix (2009)

Attendance at the TREAT-NMD International conference in Brussels to ‘launch’ the research project in November 2009, prompted sustained research to visually represent the fundamental objectives of the collaboration. This led to the experimental making of what became the *Vials Project*. Taking the common analogy that DNA is the ‘book of life’ miniature books were made approximately 1cm x 1cm with each page being made up of the four names of the components of DNA; Adenine, Guanine, Thymine, and Cytosine, therefore AGTC, repeated across the page. At random intervals through the book a ‘typo’ was inserted, representing the term used to explain a mutation in the DNA structure of an individual. These tiny books were then inserted into miniature glass vials and some of them filled with liquid. The liquid changed the ‘view’ of the book through magnification and also began the process of the disintegration of the paper.

Figure 13 *Vial + Book* (2009)

This initial studio experiment, whilst never resolved as an art work, came to represent certain criteria that became the preliminary method for the future works. The component parts of the piece were all a visual representation of something that was either known scientific fact, e.g. the component proteins that form DNA or the representation of an idea, the magnification of the water changes the view so therefore how something is seen. This

collection of component parts made up the ‘ingredients’ that informed the ‘recipe’ to make something. It was this process of collection, interpretation and experimentation that became the working methodology within the studio. The ‘ingredients’ were put together thus creating a recipe or formula -

Book=Life=DNA =Lab=Diagnosis=Typo=Seeing+Disintegration=Disease

This rhythmic and repetitive way of sorting the data seems to have emerged through the need to categorise and assign the volume of information being collected and is also indicative of the feeling of unfamiliarity that immersing the arts practice in such a scientific environment was causing to any creative response. As previously discussed the basis for the research question quickly became categorised into the objectives of *seeing* and *saying* through an interaction with *people*, *places* and *things* thus this methodology became embedded in the process -

People+Places+Things=Collecting=Words+Pictures=Things=Seeing+Saying

5.6 When Studio meets Laboratory

The research methods involved in marshalling key data and developing an experimental arts practice took place within two distinct physical environments – the artists’ studio and the laboratory. The dictionary definition for these two places is as follows –

> Studio - a room where an artist, photographer, sculptor, etc. works:
>
> Origin: early 19th century: from Italian, from Latin Studium
>
> Laboratory - a room or building equipped for scientific experiments, research, or teaching, or for the manufacture of drugs or chemicals:
>
> Origin: early 17th century: from Medieval Latin laboratorium, from Latin laborare 'to labour' (Chambers, 1998)

The creative practice at the core of this research project took place between these two environments, two separate ‘rooms’, one the place to ‘study’ and one the place to ‘labour’. The activity carried out in each can be defined in isolation of the other but the objective was to immerse the arts practice into the alien environment of science for the purposes of the collaborative research project. At this stage, it was becoming evident that whilst the project was described as a ‘collaboration’, ‘the action of working with someone to produce something’ (Chambers, 1998) the actual process for me, as a practitioner, when communicating with the *people, places* and *things,* was one of an interaction – ‘reciprocal action or influence’ (Chambers, 1998). The definition here is important as for me it gave rise to a number of questions:

Were the artworks and studio tests purely illustrative of the scientific world in which I had immersed myself as an artist? How could I make artworks that maintained their integrity whilst operating on the different planes of art and science? The 'science' part was significant, for without the collected knowledge and influence of the interaction there would not be the same impetus for the work. The 'science' however was also an interference with my normal creative process within the studio environment. This interference took the form of a constant questioning; not only of how to understand the unfamiliar language and concept of genetic mutation, but also an interference with my confidence in what I was producing. The aspects of the arts practice – the process and the presentation had to have integrity but also a verisimilitude – an acknowledgment of the acquired scientific information without producing an 'answer' to a given 'question'.

The *Vials Project* was the first experiment of this new 'mongrel' practice and therefore the first work of any sort that could be held up to scrutiny. The work remained unresolved as it failed to articulate any real meaning and therefore did not represent the complex issues that were inherent in the initial ideas for the work. However, the idea of a working formula was cemented around this working model –

Book=DNA+Vial=Lab=Diagnosis=Typo=Disease =Seeing+Disintegration=Disease

It is this naming of the studio method, within the context of the research project, that gave a currency to the ongoing speculation within the studio making and that cemented the use of the definition 'interaction' as opposed to 'collaboration'. In this context, the 'mongrel practice' was not only 'indiscriminate' and potentially 'inharmonious', but it also gave rise to a form of alchemy intrinsic to creative work, in particular the transmutation of meaning from one thing to another. It was this 'allowance' of not 'having to know' that enabled the experimentation with the methods and materials within the studio making to occur and thus led to the other works that could be termed as successful for example in the works *Presents as…* [Fig.25] and *Inchoate* [Fig.35] which used combinations of unknown and unstable methods and materials. The two rooms, the studio and the laboratory, sat in parallel as places and spaces in which activity took place; it became evident that both spaces were about investigation and seeking solutions to problems. Whilst the laboratory was an alien environment it was also, at first glance, surprisingly ordinary.

The laboratories at the Institute of Genetic Medicine and the Immuno Analysis Laboratory in Newcastle are modern laboratories containing advanced technologies. These often large rooms contain many 'blank' surfaces, long white benches and chairs make up work stations, shelving containing, mostly plastic, bottles and jars, white doors that are fridges and freezers containing samples. The microscopes are large with the images viewed on monitor screens as well as through the eyepiece, the DNA sequencing machine is large and grey. Much of what can be seen looks utilitarian with indistinct and undefined purpose. All that goes on in these rooms is hard to see, as often, the processes themselves take place within the machines. There are however small clues that point to what could be perceived as a strange world with recognisable elements; A book lying on a bench, the title hand written '*Mouse Ear Clippings, Number 4*'; A small brown bottle labeled 'Polyclonal Rabbit Anti-Mouse Immunoglobulins' another small brown bottle 'Polyclonal Swine Anti-Rabbit Immunoglobulin'; A small hand-held appliance - a '*muscle macerator*'.

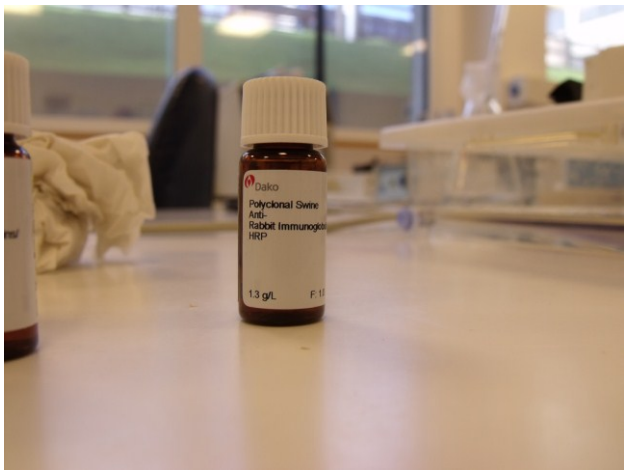

Figure 14 Lab Image (2010)

As a non-scientist, with no experience of a laboratory environment, the vernacular of the laboratory is one where objects become potent and gather meaning to themselves through clues rather than explanation. Some objects became more significant than others as the interaction progressed, for example the ‘muscle macerator’ is used to do what the name would imply so that the muscle samples can be made small enough to be used to make the Western blot. The Western blot became integral in the *Presents as…* work as the combined image of the blot and the historic photograph of the boy with the disease was used in combination with the gel material and the cyanotype method. The methods of the laboratory were used to create the artists portrait of the disease.

The approach here is one of creativity, to bring the arts practice into the laboratory, this therefore gives a new perspective to the 'finding out' that is endemic within the scientific field. Whilst the laboratory is a place to experiment, to seek solutions to a problem and therefore to find out the 'answer to something', the creative practice within this environment, whilst also a place to experiment and to 'find out', does not necessarily create solutions that can be formed into the answer to specific questions.

Rather the arts practice is an area around which to start an investigation, the artists’ studio is a physical space that ‘allows’ this to happen. At this point any making in the studio had been confined to simple methods and attempts to make 'things' using found objects,

images and paper. This resulted in the visual 'map' mentioned previously, depicting some of the data gathered through research, some sculptural forms made from paper resonate of the Double Helix structure and some glass vials containing miniature books. These processes made concrete unfamiliar images and ideas and provided a place from which to take the next steps. This process of ‘gathering’, both images and ideas, and then attempting to combine the gathered images and ideas into ‘things’ that resonated with the research themes reinforced the concept of the formula –

People+Places+Things=Collecting=Words+Pictures=Things=Seeing+Saying

The objective for this process was to create a narrative range and a set of representational strategies that could then be further explored as the research progressed. The complexity of the scientific information led to many attempts to develop a set of appropriate and innovative materials and processes within the studio that would enable the production of artwork. Ideas would emerge from different areas of influence within the collected data and then these ideas would become distilled through talking with the people in the laboratory and the network. Thus works like *Inchoate* and *Sequence Shift* [Fig.47] began to emerge though this gathering process and experimentation with different materials. This method of experimentation facilitated an arbitrary approach to the resources as I was unable to join up the thinking and links as I did not have the language to do so with any certainty of being ‘correct.’ A feeling of getting things 'right' or 'wrong' in the scientific sense remained throughout the course of the project as the complexity of the science was impossible for me to really understand. The studio became filled with 'half-truths’ and loose interpretations that allowed the creative process to develop. Many of the techniques used to hand coat the papers for the albumen and salt prints were difficult to execute but this practice of experimentation with the material was evoked through the processes of experimentation with the chemicals required. In essence there was an attempt to articulate the art practice through the language system of something other – the scientific laboratory. In a sense this creates something akin to a ‘space’ metaphor or a

‘profession’ metaphor, i.e. one practice uses the systems and methods that are in use in another practice. These practices however are often ‘tampered’ with and changed. The method therefore becomes a hybrid – hence a *mongrel* practice.

Over the course of the research this general approach and working method became the way for the artworks to evolve. This methodology did not in itself start out as ‘intended’ in so much as it developed over a period of time and only became clearly evident retrospectively. The two broad categories that always initiated the research were ‘words’ and ‘things’. The ‘words’ category tended to emerge from looking at dictionary definitions and sometimes quite random desktop searches. For example looking at the definition of the word metaphor leads to the Latin etymology and through to Aristotelian definitions through to metamorphosis which leads to change as in narrative and one thing becoming another. From this method of word finding the works for the entomology cases *Genotype*, *Phenotype* and *Monotype* [Fig.45] were created, and thus a direct interplay between the studio practice and the laboratory resonated within the created artworks. As the idea of change, metamorphosis and mutation became increasingly central to this research, the idea of physical change became central to the studio practice; in this instance culminating in an approach to the type of materials used in the studio. Initial thoughts and ‘making experiments’ were experimental in their execution with the main driver as that of creating a physical change of some kind within the materiality of the works themselves; an early example being the use of liquid in the small glass vials described earlier. Not only did the liquid change the view, make a lens, through which the viewer could see the contents of the vial, the book, but also to aid in the disintegration of the paper pages over time. This act of change within the materiality of the works became a visual representation of the act of mutation. This development continued throughout the project in *Presents as…*and *Inchoate* as in both of these works the materials use change and degrade over time and is therefore pivotal to the action of the disease that was being considered.

The key themes that have emanated from the research are as follows -

- Mutation and change
- Seeing the invisible
- Saying the invisible
- Portraiture, Presentation & Identity
- Archive & Collection

Whilst these themes appear rather broad they are all centred, in this research project, around the site of the human body and in this context the site of the diseased body. The following works incorporate in some form or another all or some of the above themes in varying degrees. The works that have been made during this research time have been created through a process of sustained investigation within a contextual framework that has, through its cross disciplinary nature, called for and allowed for, varying degrees of speculation and experimentation within the arts practice. Not all of the works are successful in terms of being resolved artworks and some of the experiments with materials and methods have failed completely in their execution. It is important to document here both the successes and the failures as all of these contribute to a body of work that has to acknowledge its lineage and where the works have come from. For without the failure, the successes would not have been brought to fruition.

The artworks themselves are a hard output, a culmination of the visualisation of a complex research process. This is then combined with interrelated methods, possibly adopted or informed by the scientific processes used in the laboratory. Along with the use of new and unfamiliar materials the artworks began to emerge. Sometimes the material itself is representative of something – an idea or a feeling whilst in others the thought process and the material process are completely separate and influenced by external sources such as the laboratory. The works below are described in chronological order to give a coherence and structure to the growth and development of the studio practice. The chronology also allows for a narrative to emerge that whilst linear in terms of the order of things happening

also demonstrates the process by which a range of presentational strategies have been explored and tested through exhibition, lectures and other forms of public output. An approach had been developed that enabled an assimilation of unfamiliar ideas and materials into the studio practice thus making the physical space of the studio a testing ground for the artworks that would make up a large element of the research project. The studio began to fill up with the accumulation of data that was being collected from my interactions with the *people*, *places* and *things* and so initially there were a number of ideas running along at the same time. I was experimenting with materials on which to lay the images that I was making through combining the laboratory diagnostics with the historic portraits and other scientific models. Agar gels were used as means to 'carry'; and hold the images suspended in liquid for *Presents as…* [Fig.23] and latex balloons and condoms were being suspended in order to test the longevity and how much weight in liquid the material could hold for the work *Inchoate* [Fig.33-34]. The cyanotype images that were exposed onto flat gels for the work *Mútáre* [Fig.44] were tested to establish the length of the drying process, as I wanted the gels to change during the course of the exhibition *Presents as….* Certain images and visualisations became instrumental to the practice such as *Photo 51*, the photograph of a shadow. Images such as this reinforced the underlying themes of the research that had emerged such as seeing the invisible, mutation and change.

5.7 Research Methods and Materials

I developed a number of strategies within the studio in order to speculate about various processes and methodologies. I used mind map software to capture on paper the various fragments and traces of ideas that at times seemed vague and 'ghost' like.

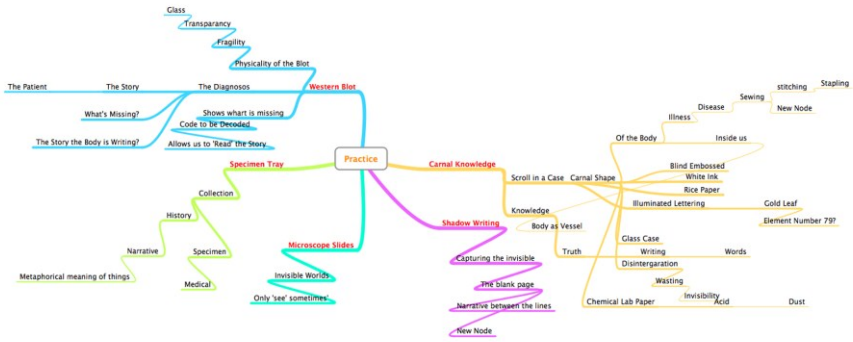

Figure 15 Mind Mapping

The visual map that had been hung in the studio was added to over time with images that I found to be relevant in some form or another. This developed into the use of collage, often putting diverse elements together, that in turn formed associations thus creating a collection of images and ideas that would provide a narrative start point – a beginning. I quickly realised, that as this collection grew, there would be multiple 'beginnings' and working on the basis of the idea of a formula to the works I had, at this stage, lots of 'ingredients' with no 'recipe'.

Figure 16 Studio Pin Board (2010)

The *Vials Project*, described previously, was an early attempt to create a physical artefact using materials that were familiar to me i.e. glass and paper. The Double Helix structures were paper based and developed with the use of inks and ways of 'scribing' text so as to generate various drawings or visual text. These works were an attempted to capture the potential for change inherent in the materials deployed and utilising the fugitive properties of liquid and capillary action, the stability of the text could be disrupted and changed.

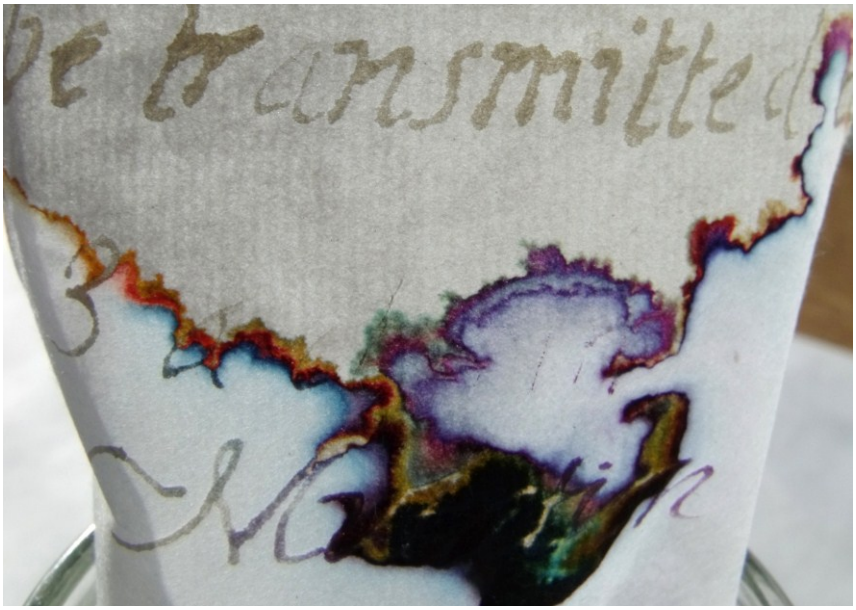

Figure 17 Ink Test (2010)

Experimentation with materials in the studio was a direct result of the laboratory exposure and an attempt to develop a formal vocabulary and aesthetic with which to represent my response to the ideas and data I encountered in the lab. The influence of the laboratory on the studio introduced the use of unfamiliar, experimental materials and also provided the impetus to revise the use of familiar materials such as ink and paper. The paper and ink experiments were influenced by the data collected that was concerned with the idea of codes, books, and the analogy that the mutation of the gene for this disease is like the typo in as book; something that cannot be easily seen or found. I began to collect printer's metal type, this had a significance and potency in the context of the attempt to visualise genetic disease through the metaphor of the 'typo'. The conventions of the printing industry, of typesetting with metal type which has to be set 'backwards' in order to print forwards resonated with the complexity of the transcription that took place within the DNA copying process. This copying and replicating over and over again had a familiarity with the old style of printing as using metal type minute changes occur with a change in printing pressure and volume of ink used. The use of the metal type evolved into using the technique of blind embossing thus scribing into the physical surface of the paper rather than just on to it. Blind embossing with metal type was technically difficult and time consuming so I began to use photo polymer plates to achieve the same result of the text being embedded into the paper surface.

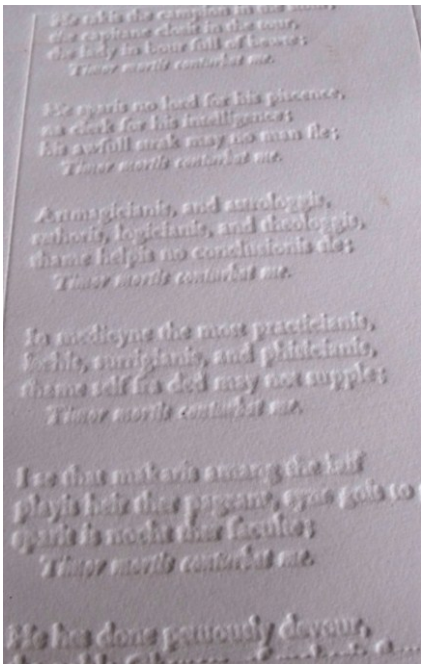

Figure 18 Blind Embossing (2010)

During visits to the diagnostics laboratory I had been recording the process of making the Western blot that is used for the diagnosis of the disease. Taking the Western blot as a base image I began to use the pattern of lines (lanes) and columns as a way to write text, forming word patterns. Throughout this process of making the use of language and word definitions was a constant activity; the meaning of words, the definition and the disturbance of these definitions seemed fundamental to the processes that were occurring in the laboratory and in the studio. These experimental images were formally similar to the patterning found in the Western blot, but were composed using the repetition of dictionary definitions and word mutations

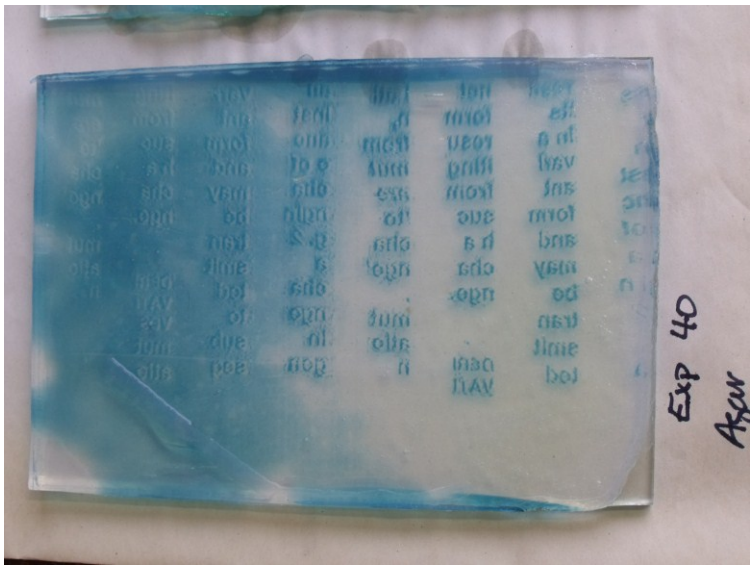

Figure 19 Gel test (2010)

My original intention had been to examine analogies and metaphors in terms of linguistics, but increasingly, under the influence of the techniques I was able to observe in the laboratory, the work had become much more about the process of making pictures not just about what is on the surface but that which is at the core of our identity, encoded in our DNA. As well as *Photo 51*, the Western Blot and the language and word definitions I was also drawn to the historic medical portraits taken by Duchenne de Boulogne in the mid 1860's and the Curschmann Atlas that had emerged through research into the history of the disease [Fig.2-3]. These images were powerful and lived on the walls of my studio for some time before they became instrumental in my own work [Fig.40-43]. The pictures did however lead to the conclusion that through artistic portrayal, depictions of data and random combinations of ideas the concept of the ‘Portrait of the Disease’ and the many forms that this may take was emerging through my studio experiments. As a working method this became key to my own understanding of what I was attempting to communicate, not only to a possible audience but also to reflect and inform on the arts practice itself. In the studio I was using the same materials, the text, the blot and the same images to develop a narrative that was a portrayal of the disease that was being developed in the laboratory. It was like telling the same story over and over again but changing the order of events, combining the same images, texts and materials in different

ways to create multiple narratives that all led back to the same starting point. The starting point was that of something being absent, in the case of muscular dystrophy, the dystrophin gene.

At the end of this period of experimentation there were a number of creative works and experimental pieces in the studio. These were the *Vials Project*, the *Double Helix* Sculptures, paper-based experiments using metal type, photo polymer plates that were used for blind embossing, printing inks and water. I had also been using stacked laboratory glass and clear film in attempt to photograph light and shadow; an idea that resonated with the capture of shadow as in *Photo 51*. At this time I installed the *Test Tube Tests* in the studio. I photographed the changes that took place with the text and the blotting paper over a period of time. Again in this work there was embedded the formula of collected representations, the test tube, the Whatman Filter Paper, papers used in the laboratory, the word definition of mutation, the liquid disturbing the text thus bringing about a change within the materials. It was this piece of work that became used as the primary images on the Language Lab website (Wilde, 2009).

Figure 20 Test Tube Tests (2010)

6 Research Outcomes: The Artworks

6.1 Works on paper

The ideas about portraiture and the 'portrayal of the disease' had led to the introduction of old photographic methods into the studio. These were not only reminiscent of early scientific experiments but the processes themselves were unfamiliar to me and presented a certain difficulty of control and yet offered potential for experimentation with methods and materials. The use of the cyanotype method and those of making albumen and salt prints was a working method that gathered together certain ingredients and stimuli that were then put together to form the basis for the studio experiments. The links between the ingredients used were often very linear and reminiscent of the formula discussed earlier for the vials project. For example the original cyanotype process invented by Sir John Herschel (1792 - 1871) in around 1839 was also commonly known as the blueprint. The analogy for DNA is that of being a 'blueprint' for life. The images taken by Duchenne (1862) were used for the disease diagnostics and so when combined with the cyanotype process make a portrait of the disease that not only have an historic relevance, but also a link to the ‘blueprint’ metaphor that became synonymous with the genetic information which was undiscovered at the time that the photographs were taken. The formula could therefore be written as -

Photograph+Blot+cyanotype=Diagnosis=Disease=mutation=blueprint

The use of albumen prints and salt prints were a direct reference to the historic working methods of the original photographs. The images in the *Album de Photographies Pathologiques* by Duchenne are albumen prints (Duchenne, 1862).

During the making process within the studio there were often a number of methods and influences being explored in parallel. There seemed to be multiple avenues of enquiry

that ran into one another and/or separated from one another with different themes merging to create the basis from which to make the works. The links made by me as a practitioner between the methods, materials and influences could be tenuous and sometimes unfounded on any factual basis. The collage method of joining together disparate pieces of information enabled me to create new connections between the materials in a visual form that echoed the principle of mutation governing the disease.

Figure 21 Albumen Print (2010)

From looking at 'images of disease' and from my exposure to the laboratory methods and techniques, studio processes through which to execute the ideas for new works were developing. As discussed earlier I had been exploring the notion of physical change within the materials that I was using i.e. the ink on paper being 'disturbed' by the introduction of liquid. The methods used for the images that I was collecting ranged from early photographic methods such as the albumen prints of Duchenne de Boulogne and the photogravures of Curschmann to the lithographs of Haeckel. Haeckel, like Gowers

used drawing as a primary means of illustration and was a strong influence on the *Sequence Shift* [Fig.32] work discussed later in this chapter. I was experimenting with the cyanotype process that uses chemical reaction and UV to produce the blue images that are often referred to as *blueprints* and with hand coating papers to make salt prints and albumen prints. This adoption of historic techniques for me added veracity to the work that evoked again the idea of the mongrel practice, a mixing together of materials and techniques that was direct and simple amidst the volume of often incomprehensible scientific data. This led to the ‘recipe’ of -

Portrait = Individual + Life = Story

Combining historic medical portraits with the contemporary 'disease portrait' of the Western blot seemed to capture an intrinsic 'meaning' in the work that was acquired through the acknowledgement of 'what had gone before'. In the case of these works the action of the making entailed the adoption of the processes, like the albumen prints, that captured the original images of the patients in the clinic of Duchenne de Boulogne.

A body of work therefore developed that evolved from the theme of portraiture but where the action and process of the making and the authenticity of the materials used, all contributed to the narrative, the story, of the disease in so much as these works are pictures of people with disease and/or pictures of people with the diagnostic image of the disease. This 'picture making' methodology is the combination of a thought process and a material process that when joined allow for the emergence of a collage of images and ideas that visually represent the story that the diseased body is writing.

Retrospectively, it is evident to me as a practitioner that there was a fundamental drive in the use of certain methods and materials that would add a validity, and somehow an authenticity to artworks that were the product of this mongrel practice that at times felt unstable and ill at ease.

6.2 Presents As...

The *Presents as …* exhibition consisted of a body of work that evolved from the studio experiments with new and unknown materials as outlined previously in this chapter. The approach to this collection of artworks was driven by the knowledge that an exhibition of the research output would be held. The first manifestation of *Presents as...*was in the studio where the works were displayed as for a gallery exhibition for the purposes of a supervision meeting in order to discuss the progress of the research. Installing the work into the studio in an 'exhibition ready' way allowed for the problems of the installation to appear and therefore be addressed in terms of how the work was to be displayed. The ideas in terms of the materials and images used had come from the earlier studio experiments with the photographic process of cyanotype. I had been testing the use of agar gel in order to make a transparent 'carrier' for the image that I was creating. The electrophoresis technique used in the laboratory to make the Western blot had been something that I had hoped to develop but the equipment required and the cost of the raw material, along with health and safety issues made this difficult to execute.

Figure 22 Cyanotype Petri Dish Portrait on Agar (2011)

During the course of the research several visits were made to a diagnostic laboratory to observe the methods and techniques used in order to diagnose patients that had presented to medical practitioners with symptoms that were often linked to a group of inherited muscle disease. As a result of these visits the studio practice began to explore methods of interpreting and 'illustrating' the laboratory techniques. This investigation resulted in a group of studio 'experiments' that tried and tested various materials in order to achieve something that resonated with the experience of observing the technician in the laboratory. In essence the studio practice itself became an act of experimentation with the studio becoming a place where the outcome of the work was unknown and the materials used unpredictable. The work seeks to explore and engage with a number of themes and ideas but in essence is about how we 'see' and how we 'say' in the context of genetic disease that is caused by a mutation. The exhibition was made up of three main component parts, *Presents as*…*Family Matters*, *Mútáre*, and the four entomology cases, *Clutch*, *Phenotype*, *Genotype* and *Monotype*.

The space in the foyer of the Bio Sciences building where the work was exhibited is not a conventional gallery, although artworks and exhibitions are on display there on both a permanent and a temporary basis. *The Presents as…* exhibition was displayed in a gallery type manner referencing the 'rules' and conventions of the white cube space, whilst the vessels used for display, i.e. the Florence flasks, petri dishes and entomology cases, all had a scientific basis. These methods of display therefore created a dual narrative that reinforced the mongrel tendency of the project in bringing together the physical realities of 'showing' art and science.

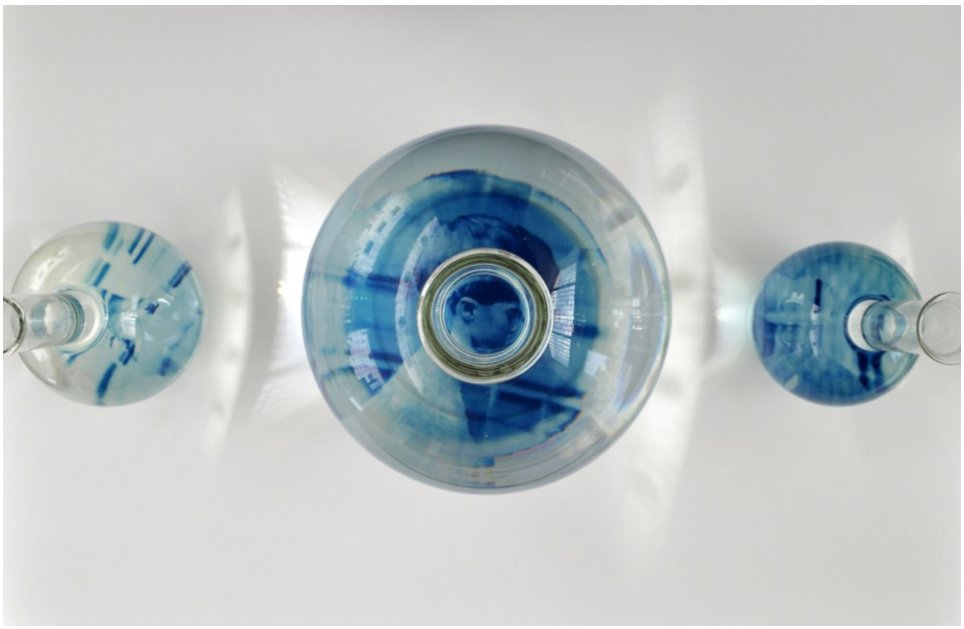

Figure 23 *Family Matters* (2011)

The entomology cases were placed on white plinths and labelled in the conventional way with a label denoting the size of the object size and material used. The wall based works *Mútáre* consisted of four framed works hung on a white painted wall and lit from above. *Presents as…* is displayed on and in a large plan chest that is white. The portraits are placed and held in conventional laboratory glass Petri dishes and watch glasses. The three Florence flasks on the top of the plan chest are supported on clear acrylic stands and filled with water. In the water the portrait images of the boy and the blot float freely. The uses of the gallery type conventions of display provide an immediate frame of reference for the audience. The work is to be viewed but not touched, the whiteness of the walls, plan chest and plinths provide a sterile and laboratory feel to the work as well as to the 'untouchableness' of the gallery exhibit. The audience is therefore expected to, and expects to, view the works at a distance.

The nature of the building itself however, as a research institute conveys a predetermined idea that the space is for the purpose of gaining and sharing knowledge. By its proximity to both the idea and the physical space where knowledge is 'mined' conveys a frame of reference to the exhibition audience that perhaps there is something to be found out here,

there is a meaning both within and ascribed to the actual work, the audience can therefore expect to find something out and quite legitimately *ask what does this mean*? The proximity of the artworks to a space that is about knowledge it could be argued changes the audience perception of the expectation of what will be viewed. This combined with the literature produced, in terms of invitation and information leaflet set up a predetermined reading frame that enables an audience understanding and therefore legitimacy to the question *what does this mean?* and the expectation that an answer will be received. The body of work ranges from the exploration of the words as physical entities to the aesthetic beauty that can be found in diagnostic techniques such as the Western blot and in the medical portraits of Duchenne de Boulogne (1862).

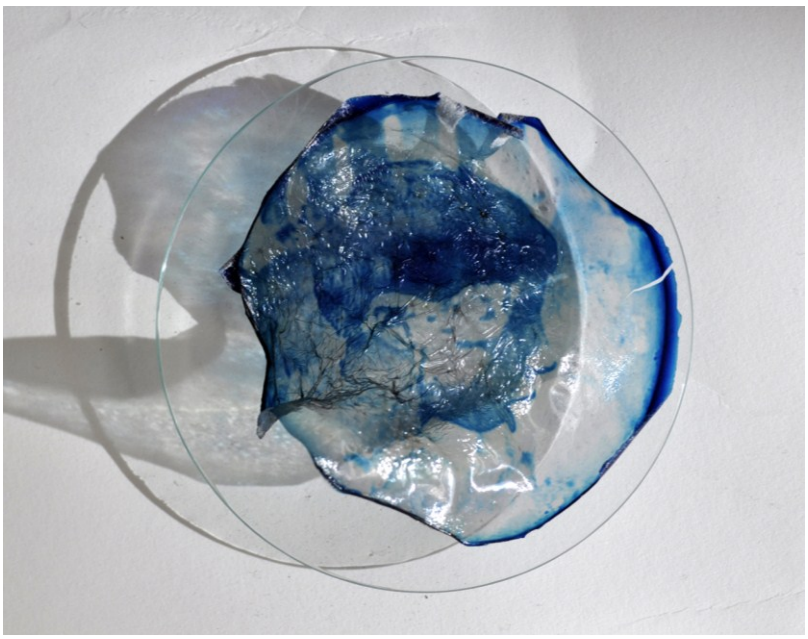

Figure 24 Dried Gel in a Watch Glass (2011)

The component parts of the exhibition drew on the themes that were emerging from the research and therefore represented the ideas of the diagnostic image as portrait of a disease in the central work *Family Matters* which consisted of the plan chest and the flasks. The image of the boy was used over and over in the work in various representations and combinations with the image of the Western blot and text. The drawers of the plan chest were filled with petri dishes containing the cyanotype image on

an agar gel thus creating a kind of archive of portraits. The images on the gels were made over a period of time and therefore dried and degenerated at different speeds. The combined material of the cyanotype and the agar is unstable and therefore difficult to predict how the material will respond to UV light and humidity. The petri dishes aged at different rates with some developing various mould growth whilst others stayed clean. The plan chest then represented to me the ‘archive’ of the disease, the replication and degeneration occurring repeatedly over a period of time.

The Florence flasks contained a much larger cyanotype image on a gel that was suspended in water. Due to the reflective and magnification properties of both the liquid and the glass flask the gel portrait ‘disappears’ and distorts, and can only be seen from certain angles and views. This appearing and disappearing seemed to represent the invisible becoming visible but also the randomness of such visibility. The images within the liquid aged at a much slower rate than the petri dish gels that were exposed to the air and therefore remained preserved for some time, yet untouchable through the boundary created by the glass wall of the Florence flask.

Figure 25 *Presents as...*Centre for Life (2011)

The work *Mútáre,* from the Latin *'to change'* consisted of four framed wall mounted works on paper. The images were made using the agar gel as a carrier for the cyanotype image which was made from a combination of the Western blot image and text which read 'now you see me now you don't'. The gels were made to be the same size as the Western blot, 13 x 12 cm, and the text was placed in the gaps where the dystrophin band should have appeared on the Blot of a person not affected by Duchenne muscular dystrophy. The gels were left to dry for a period of time on the paper before being framed. The nature of the drying process and the timing of making the gels and framing the works meant that the pieces physically change during the course of the exhibition as the gels slowly dried out. This work therefore 'mutated' over the period of the exhibition before stabilising when fully dried out.

Figure 26 *Mútáre II* (2011)

The work *Clutch* consisted of 12 glass ‘eggs’ containing the representation of the embryo of a Zebra fish (Danio rario). The Zebra fish is used extensively in bio medical research due to the transparent nature of the embryo and therefore the developing fish. This allows for the growing fish to be observed and monitored for the effects of genetic change and mutation (instigated by the researcher), whilst the fish is alive. The Zebra Danio fish all look very similar when swimming in shoals in the large and numerous tanks in the research facility, and yet whilst genetically the ‘same’, some with a mutation become ‘different’. The glass embryos were handmade using borosilicate glass which is commonly used to make laboratory glass. The fish embryo was made first with the glass ‘egg’ being blown around it. A number of the ‘embryos’ were then sandblasted, giving them a more opaque look. The ‘eggs’ were then filled with water which not only magnified and distorted the ‘embryo’ inside but also made the sandblasted ‘embryo’s almost identical to the clear. The ‘embryo’ that was different therefore, at first glance, looked the same. By containing the glass ‘eggs’ in the entomology case they become not only untouchable but also represented the idea of scientific collection. The collection, containment and observation of something that cannot always be seen and is therefore sometimes invisible.

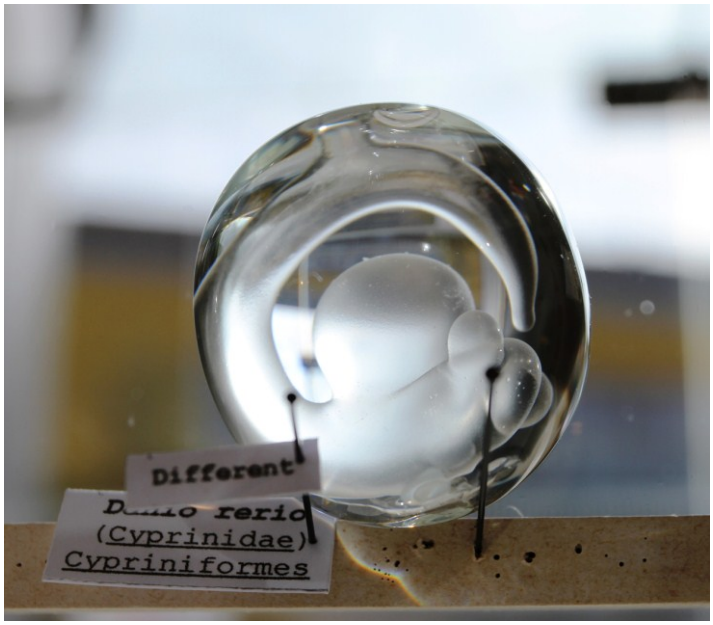

Figure 27 *Clutch* (2011)

The three other entomology cases in the exhibition were grouped together as a collection but displayed on separate white plinths. These three cases all contained variations and representations of a text that was made up of individual words. The words were all synonyms of the words ‘typo’, thus giving the words ‘glitch’, ‘flaw’, ‘solecism’, ‘error’ etc. the words were all displayed differently within each individual case. Case 1 *Monotype* was made using metal type that was typeset to form the words – these words were then inked and printed on small strips of paper forming labels. Case 2 *Phenotype* consisted of tiny gel discs on which a cyanotype image of the word had been exposed. These small gel discs were then placed on entomology specimen cards and pinned in to the case as one would pin a collection of insects. The small discs of gel dried over time leaving a trace of the word. The third case, Case 3, *Genotype* contained agar gel discs suspended in Glass Fumigant Cells. The glass cells were filled with water and the discs with the text exposed on it with cyanotype were suspended in the liquid. These three entomology cases formed a collection, an archive of dissolving words that all read as the same thing, yet looked and sounded very different.

Figure 28 *Phenotype* detail (2011)

6.3 Intersections

*Intersection*s were an event that was organised for the Science Festival that was held in Newcastle upon Tyne in April/May 2012. The event was organised and curated by me with a panel discussion about what happens at the intersection of art and science. Does science influence art and can art influence science? What actually happens when these two disciplines meet? What are the benefits and difficulties for those working in these kinds of relationships? (Centre for Life, 2012)

The exhibition space was in the International Centre for Life, Newcastle which is a science museum that is open to the general public. I invited artists who were working alongside or heavily influenced by science in their practice to contribute work to the exhibition. The final show included four artists – Helen Gorrill, Daksha Patel, Dr John Lavell and myself. The panel discussion took place one evening during the science festival event where the question '*Can art influence science and does science influence art?'* was put to the panel members.

Figure 29 *Intersections* Invitation (2011)

The panel, which was chaired by Ian Simmonds, Communications Director of the Centre for Life, consisted of Professor Volker Straub, Institute of Genetic Medicine, Professor Christine Borland, Northumbria University and Dr Simon Woods, PEALS at Newcastle University. This event, like the Language Lab website, was a strategy employed to disseminate this research investigation and the artworks produced to a wider audience and also to engage with the debates surrounding art and science communications in a wider arena. The audience was a mixture of those from the arts and sciences and the panel discussion ranged broadly across the question of influence from one discipline to the other.

Whilst there was no quantitative analysis of the discussion that took place the emerging themes were those of the relationships that exist between artists and scientists and the positive and negative issues that can emerge from this. Whilst the conversation ranged broadly across the topic it was difficult to discern any firm attempt to address, that whilst science influences art, what are the influences that art may have on science and how do they manifest themselves?

The work '*Sequence Shift'* that I installed for the *Intersections* exhibition was rooted in a combination of studio experiments that I had been making using the technique of albumen printing. The inspiration for these works has come from looking at the illustrations of Ernst Haeckel (1834 – 1919). Haeckel's artworks depicting collections and patterns from nature are instantly recognisable due to the precise nature of the work in capturing the geometric shape in natural forms.

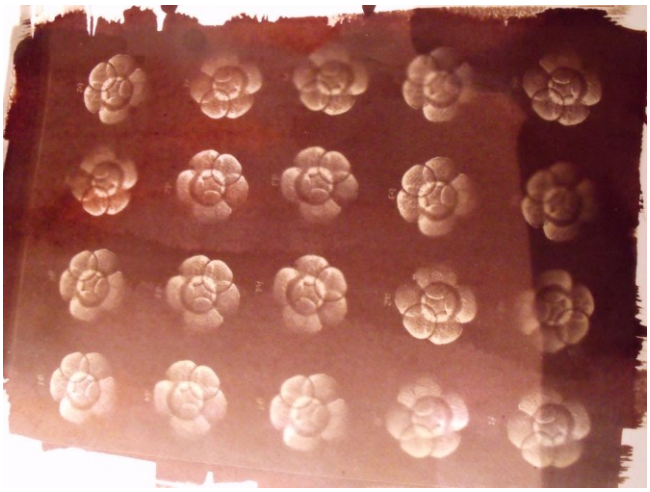

Figure 30 Haeckel inspired albumen print (2011)

Using a base image of a Zebra Fish combined with text of the definition of ‘mutation’ embryo I had been experimenting with the repeat pattern and replication of images over and over again. These experiments used the method of Albumen Prints that were proving to be challenging to execute as hand coating the papers to give an even surface and successful exposure takes a certain level of skill. For these works I was again working to a formula of combining the method and the material to resonate with the image. The base image that I was working with consisted of the -

Fish+Mutation+Cell Division

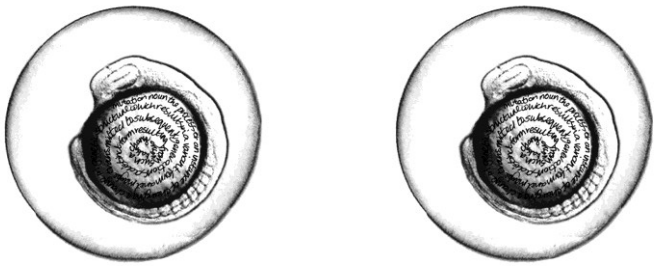

Figure 31 Sequence Shift Screen print (2012)

During these experimental works I was also exploring screen printing onto different materials, such as transparent film and art papers. The final work developed into the use of wallpaper as I was keen to make a counterpoint to the work with the very scientific aesthetic that had been so present in the *Presents as...* exhibition. The works in this show had all been contained within glass vessels, drawers and entomology cases thus creating a boundary or border between the viewer and the work. By using the wall paper I wanted to create a more 'open' and accessible view of something that is always 'contained' within, in this case the cell. My original concept had been to 'wrap' the work around and enclosing the viewer as in a 'cell', thus taking something that is normally inside (the cell) and visualising it outside (the physical body). I therefore designed and printed (with much help from the print technician Alfons Bytautus at Northumbria University) 40 meters of wallpaper.

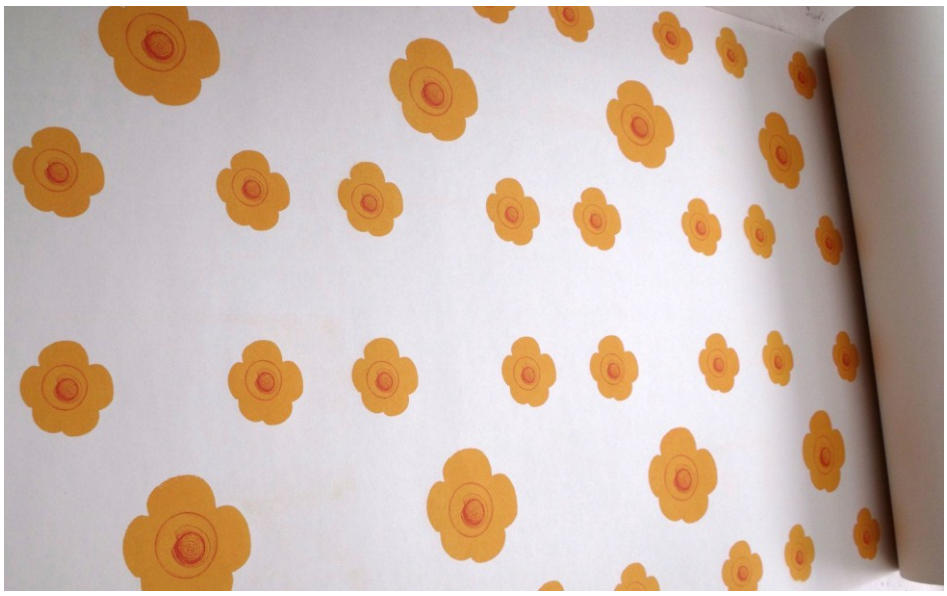

Figure 32 *Sequence Shift* Wallpaper (2012)

The installation of the work along with those of the other artists in the exhibition proved to be difficult as the space allocated was much smaller than had at first been envisaged. Curating the show at the Centre for Life, and organising the panel event, also proved very time consuming and not without difficulty. The installation of the work *Sequence Shift* was for me unsuccessful as I was unable to achieve the sense of enclosure for the viewer that I had hoped for. The wallpaper proved difficult to hang as the use of wallpaper paste was prohibited on the walls that were being used and therefore the seams of the paper were far from perfect. In retrospect the work did not fulfil my original concept of what I had envisaged although this was mostly to do with the installation spaces.

6.4 Inchoate

The work *Inchoate* developed as a sequential step on from *Sequence Shift* which as a work I had intentionally moved away from the scientific feel of the glass and gels to turn the view from the 'outside' to the 'inside'. This idea translated into the working idea of using 'squidgy' 'soft' materials therefore more organic and 'bodily'. At this time I had a definite intention to change the practice and take away certain 'signposts' to the science that seemed to be overwhelming the practice and to shift the 'reading frame'. By changing the narrative focus away from science I wanted to move from a feeling of 'knowing' and to a feeling of 'imagining'.

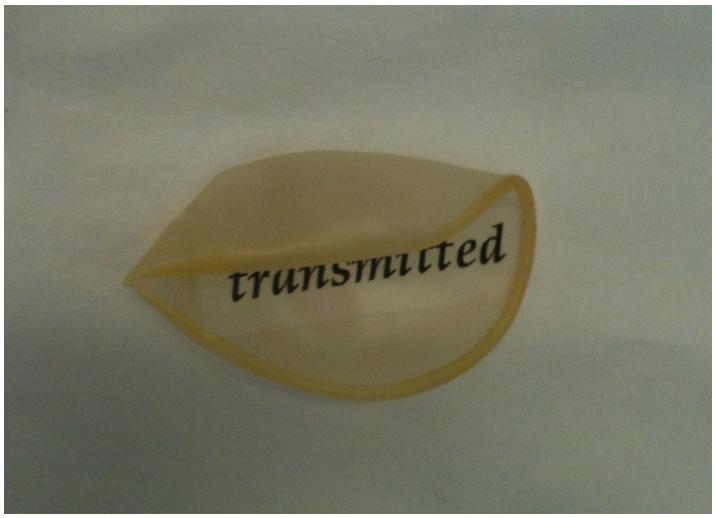

Figure 33 Burst balloon detail (2012)

The primary role of the condom in this work was not, as may first be imagined, the representation of the site of reproduction and or the ethical issues surrounding genetic counselling, but more the organic and bodily 'feeling' that is attached and can physically be felt through the latex material of the condom. Initial studio experiments had been made using latex balloons as I was deliberately shying away from using the condom as I felt that the baggage of association was too great and was potentially inappropriate for the work. The condom however, as a material, lent itself to the task and 'worked' in terms of the

shape and feeling that I was able to achieve. Initially I made ‘egg’ shapes from agar gel and placed this inside the condom suspended in water with the intention of exposing an image inside the agar egg, I had also experimented with using clear glass marbles with text. Technically this proved to be very complex and with the added opportunity to show this work at the opening of *Baltic 39* I felt a certain pressure to resolve the work and make it exhibition ready. I therefore used the Zebra fish embryo image from *Sequence Shift,* printed onto acetate and placed this image inside the condom.

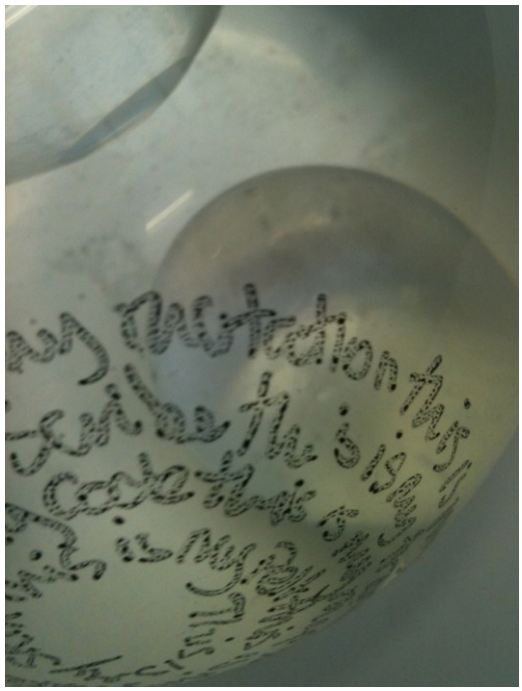

Figure 34 *Inchoate* detail (2012)

By suspending the condoms at different heights my intention was for the viewer to see the image from all angles, or not at all, depending on their position to the work. I had also hoped that the viewer would be able to move amongst the suspended pieces thus being enveloped by and ‘inside’ the work itself.

Apart from a small number of tests in the studio the work was installed for the first time in *Baltic 39*. Due to the nature of the work being fragile and containing water health and safety dictated that it be placed where it could be 'contained'. This disabled any intention of the viewer being permitted to walk amongst the work but the space in which the work was installed added another dimension as it was relatively narrow and 'opened' up behind the piece. This version of the work, as it is so site specific, allowed for over 60 condoms to be suspended. The specific longevity of the piece was unknown as the work would degrade and collapse over time, this proved challenging to the gallery space overtime.

Figure 35 *Inchoate* Baltic 39 (2012)

6.5 Shadowland

Shadowland is a collaborative work produced by myself and Professor Volker Straub of the TREAT-NMD network. The premise for this particular work was to explore, through an act of collaboration, what happens at the intersection of the worlds of art and science and how these two disciplines may come together to produce a creative work that is influenced by, and takes its methods and materials from across the two disciplines. The project was instigated by the ESR Genomics Network at Edinburgh University who are undertaking research into the 'spaces' that can be developed through such interdisciplinary projects. As Professor Straub and I have an existing relationship that involves our interaction across the disciplines of art and science this work was a natural progression that enabled the production of a work that was the outcome of a direct interaction. Through initial discussions, and with the underlying idea of 'Photo Poetry', it seemed appropriate to look at some specific scientific research methods and tools that are used by Professor Straub during his working activities. From these discussions and through looking at various imaging techniques we decided to look specifically at MRI imagery. Not only does Professor Straub use MRI as a diagnostic tool but it was also felt that the imagery itself provided a lot of scope for artistic intervention. In the context of this thesis, the MRI represents another method of visualising the disease of Duchenne muscular dystrophy and therefore, like the Western blot, is a medicalised portrait of the disease.

Magnetic Resonance Imaging (MRI) is a type of scan used to diagnose health conditions that affect organs, tissue and bone. MRI scanners use strong magnetic waves to produce detailed images of the inside of the body. The images appear as 'slices' through the body and are tones of black and white and therefore appear in grayscale. As Professor Straub and I discussed what we were 'seeing' when looking at an MRI film it became clear that a double narrative was emerging. On the one hand the clarity of the trained eye – seeing each muscle and bone as the body passes through the scanner whilst on the other - a

kaleidoscopic pattern of light and shadows. Images combined with text were then projected through glass sheets to create light and shadow.

Figure 36 *Shadowland* Test (2012)

The moving image of shadow and light appeared as a kind of ‘binary system’ with each collaborator ‘seeing’ something other whilst actually looking at the same thing. Further discussion took place around the theme of the two stories, i.e. ‘two sides to every story’ and the idea of inside and outside, and the language associated with light and shade, light and time and familiar sayings such as ‘beyond a shadow of doubt’ and being a ‘shadow of one’s former self’. I used a Praxinoscope to deconstruct the moving image of the MRI and as the Praxinoscope was spun a succession of still images produced an illusion of movement. Text was incorporated into the moving image thus making a physical representation of the word and the image. The spinning images were recorded thus giving

two parallel video films - one of the original MRI scan and one of the artist made images and text.

Figure 37 Praxinoscope Test Images (2012)

6.6 The Unsolved Case (Der ungelöste Fall)

Further to our discussions and collaborative approach on the *Shadowland* project Professor Straub then told me about the *Unsolved Case* panel (*Der ungelöste Fall*). This panel is made up of medical experts from around German speaking European countries (and beyond) to consider undiagnosed medical cases. Doctors put forward patient cases for selection to go before the panel of experts that come together once a year. The panel members, who are all experts in their respective field of often what are classed as 'rare diseases', are sent all of the available patient information in order to review the case before the panel meets. The proposing doctor of the selected case and the patient and family members are then all invited to attend the panel. The doctor of the patient will then present the case and the panel members have an opportunity to examine the patient and to talk to the doctors involved in the direct treatment of the patient and to discuss the symptoms with the patient and their family members. It is hoped that through this process of review and discussion that the shared expert knowledge of those participating can be drawn together to form a conclusion and hopefully a diagnosis which will lead to further help and treatment for the patient.

For some patients and families the *Unsolved Case* (*Der ungelöste Fall*) panel is the last resort as to get to the point of being proposed to the panel for consideration all other medical and treatment options would have been explored. It was clear that for Professor Straub, speaking in the context of our work on the visualisation disease, that at this panel event he was able to physically 'see' the disease presenting in the patient but unable to 'see' the cause of that disease.

At this time Professor Straub was in the process of reviewing a case for the *Unsolved Case* panel and he had been sent an MRI film of a young girl with an undiagnosed disease to review. After going through the appropriate channels for ethical clearance it

was decided that provided the images were anonymised I could use them as a basis for some new work.

The resulting works consisted of 6 large screen prints overlaid with a hand drawn tracery image that was suspended on clear film in front of the prints. This method of display created a shadow of the tracery on the actual screen print image.

Figure 38 *The Unsolved Case (Der ungelöste Fall)* (2012)

The screen prints were printed using a pearlescent powder within the printing ink that added a translucent shimmering quality to the images – 3 of which were white and 3 of which were black. The installation also had a 2 minute looped video with audio that was taken from the original MRI scan film for this particular patient case. The audio was that of a repeated breath and heartbeat looped over an image of the 3 moving sections of the MRI 'slice' as it moved through the patient's skull. This work, as with the *Presents as…* exhibition, was installed in the Bio Sciences building so therefore not a traditional gallery space. To counteract the openness of the foyer space the walls for hanging were arranged to form a small enclosure so that the viewer entered the space to view the TV monitor and the 6 screen prints. The requirement for the viewer to step 'into' the

installation came closer to the idea of ‘wrapping’ the work around the viewer that I had wanted to achieve with the *Sequence Shift* work.

Figure 39 *The Unsolved Case (Der ungelöste Fall)* (2012)

This use of black and white and greyscale as a colour palette for these works chimed with the ideas of a binary system of ‘seeing’ by the two collaborators that has emerged during the research of the *Shadowland* project. The background story for the origin of the MRI scan that was used was powerful and grounded very much in the facts and day to day issues that present themselves to clinicians such as Professor Straub.

6.7 Conclusion

In immersing the arts practice within the scientific environment as outlined above it was possible to identify the methods and materials used in the arts practice, the themes and lines of enquiry that began to emerge and the influences that became apparent from the collected data. Some of the works were more successful than others with some pieces never being resolved. It is important however to document the studio practice, as this working environment was the site for the research to take place. Whilst this investigation sits within a contextual framework, as outlined in previous chapters, the creative works themselves still follow the conventions of a creative practice that is responding to a range of criteria, in this case the world of science and genetic disease.

In the approach to each work I have outlined the influences that have become apparent from the data collected and how this data has been used to develop the works. There are a number of themes that have emerged throughout the project and these themes of disease portraiture and mutation and change have continued to be used and replicated within the artworks. The works *Inchoate* and *Sequence Shift',* by not 'telling' so much in the way of a 'story', invites the viewer to create a narrative, whilst the work '*Presents as…*' had much more of a complete structure i.e. this is the boy, this is the disease, this is what happened. There was less room for the viewer/audience to attempt to, or to want to, complete a narrative in this work, whereas in a more ambiguous work like *Inchoate* there are less narrative clues, hence the work invites more freedom for imagining and affords a space for a narrative to be constructed. *The Unsolved Case* (*Der ungelöste Fall*) exhibition is a visual narrative that is drawn directly from a contemporary and unsolved medical case, thus placing the viewer in a 'real time' environment and within a story that resonates with a person living with a disease.

6.8 Images of Artworks

In the following pages Figures 40 to 51 depict a visual recording of the work that took place within the studio and of the completed works.

Figure 40 Studio paper and ink tests (2009)

Figure 41 Studio gel tests (2010)

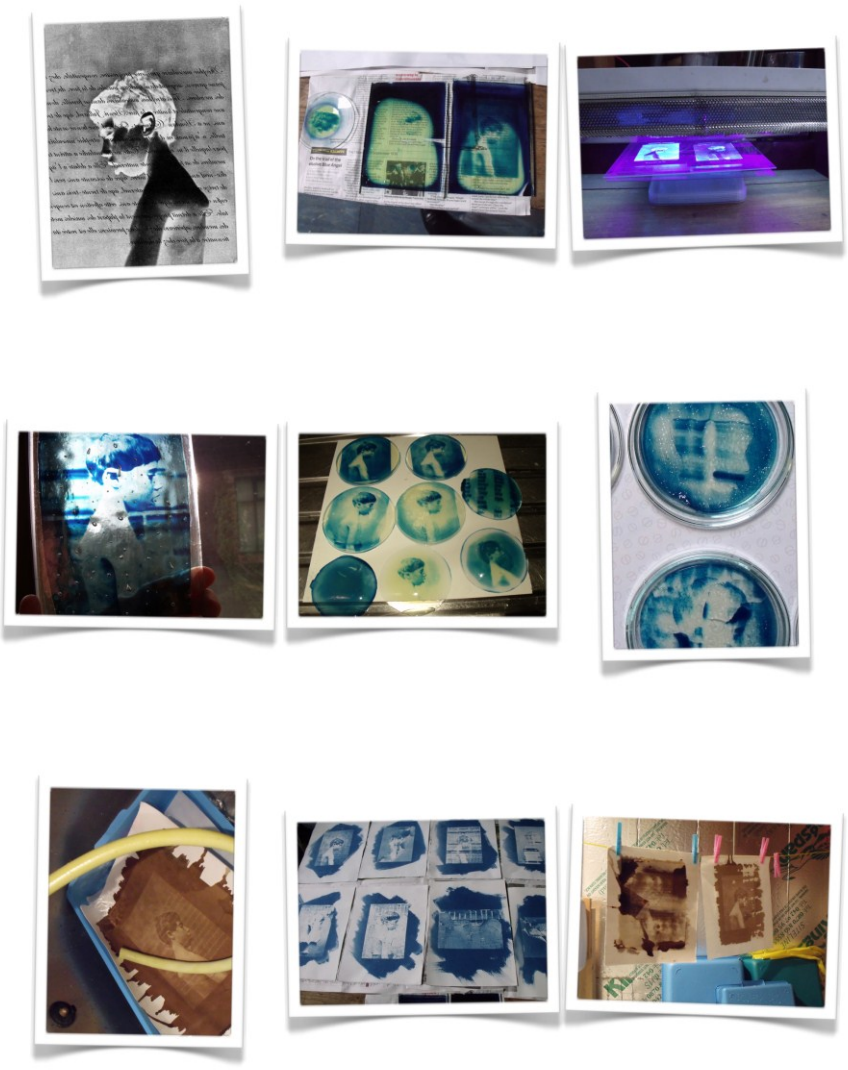

Figure 42 Portraits (2010)

Figure 43 Test Tube Tests (2010)

Figure 44 Albumen and Salt Prints (2011)

Figure 45 *Presents as...* (2011)

Figure 46 *Mútáre* (2011)

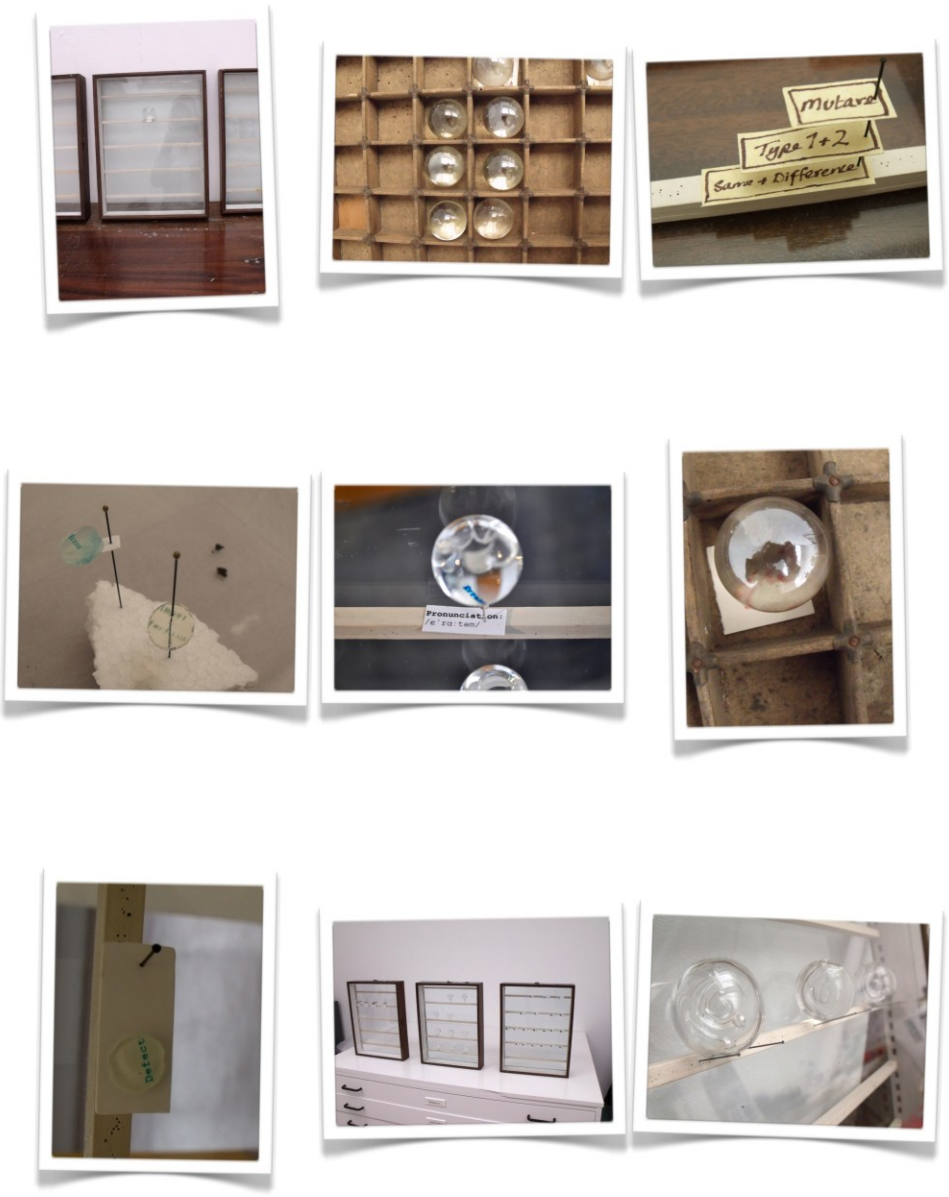

Figure 47 Entomology Cases (2011)

Figure 48 *Inchoate* (2012)

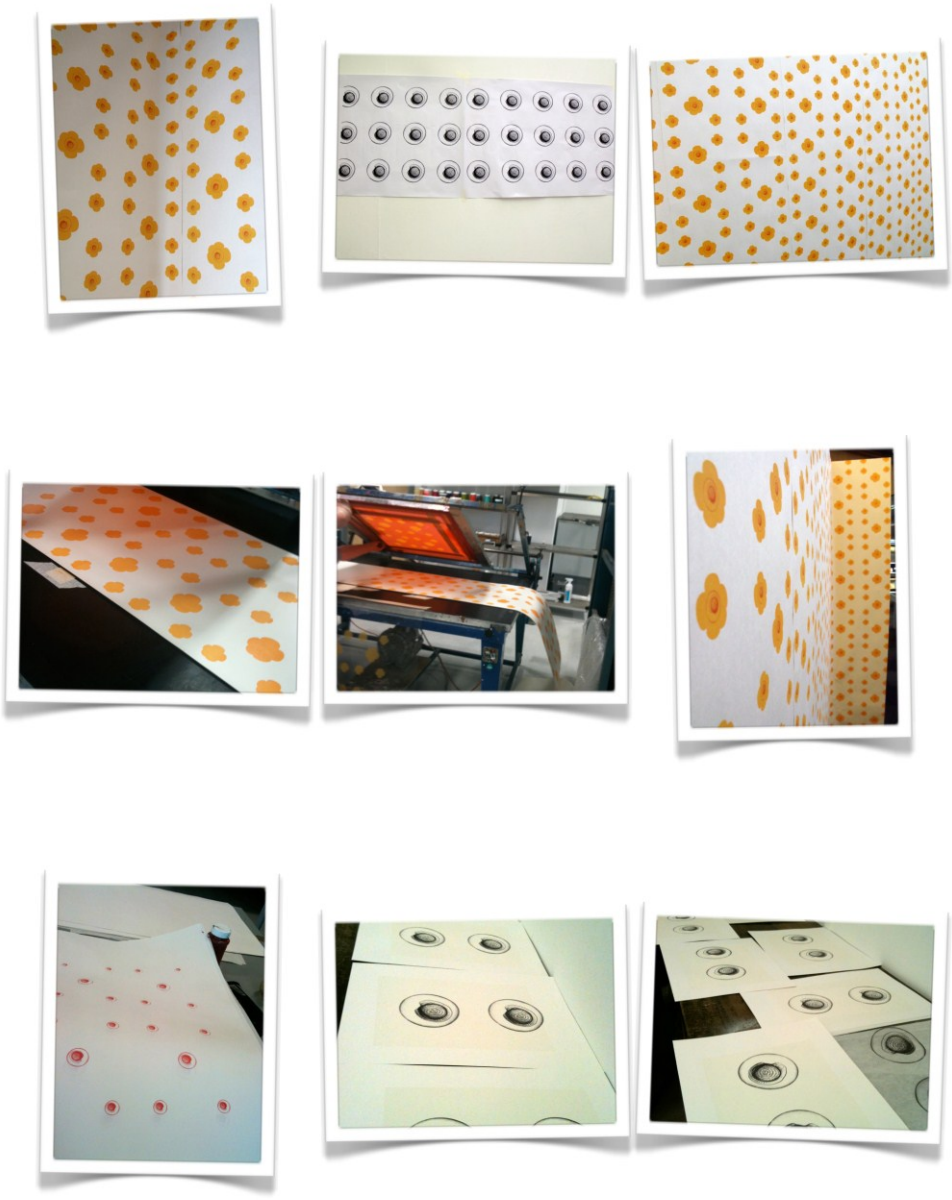

Figure 49 *Sequence Shift* (2012)

Figure 50 *Shadowland* Tests (2012)

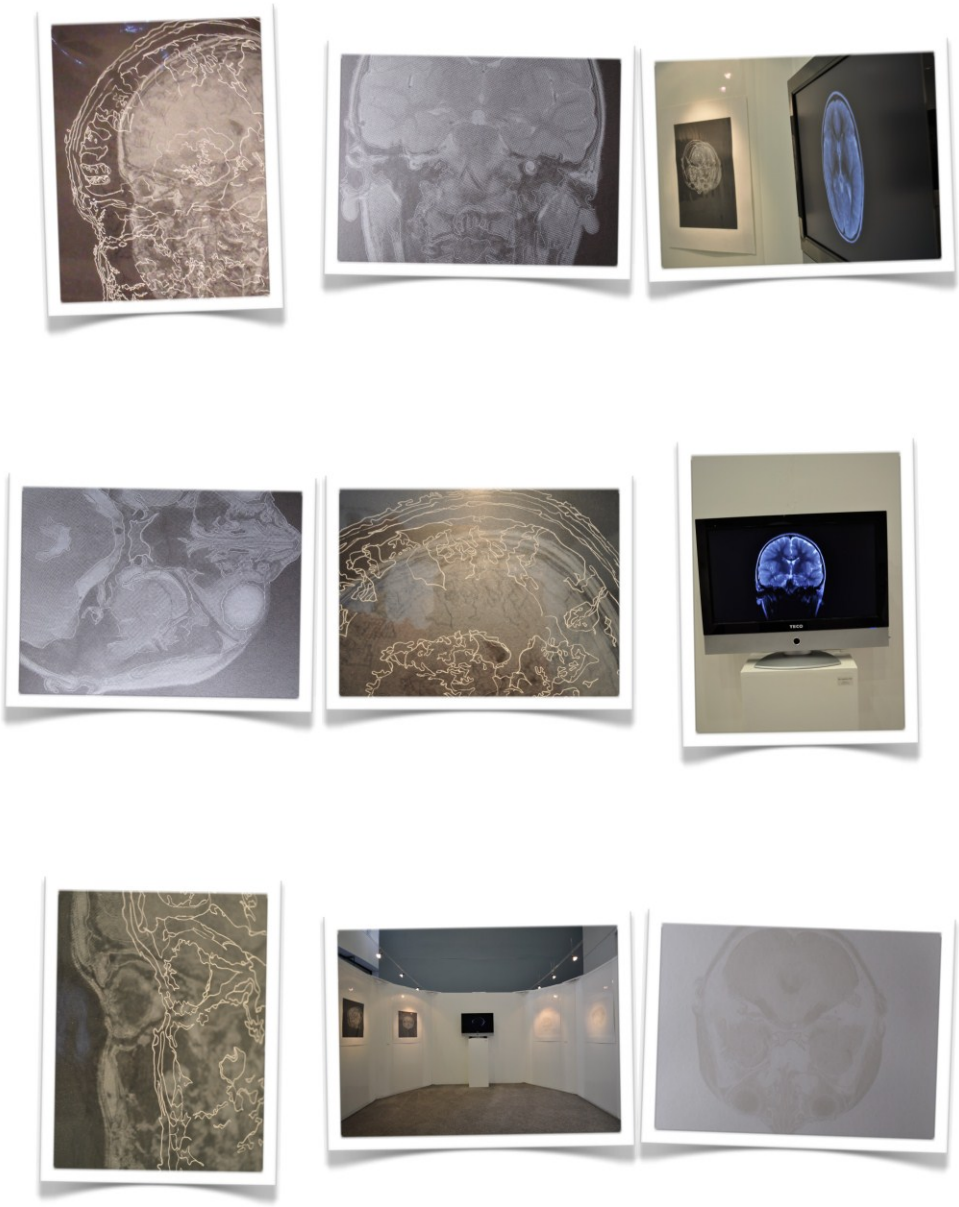

Figure 51 *The Unsolved Case (Der ungelöste Fall)* (2012)

7 Conclusion

7.1 The Research

Underpinning this doctoral project *Seeing & Saying: Visual imaginings for disease causing genetic mutations* is a central research question that considers how disease has been visualised, and how fine art practice can be instrumental in the processes of representing and understanding one specific disease. Rooted in practice-based research methodologies, this investigation has focused on the difficulties of communication in one specific area of the bio medical sciences, namely, a specific genetic disease, Duchenne muscular dystrophy (DMD). Whilst this disease presents in the physical body, the cause of the disease, the genetic mutation, is invisible to the naked eye and as demonstrated in the review of literature, since the 'genetic revolution', it has become increasingly necessary to communicate complex scientific information to audiences outside of the genetic field of expertise. Therefore how we *see* and how we *say* disease i.e. how disease is articulated and visualised through language, photography, drawing, models and graphics, has changed. The use of metaphor, and the construction of such metaphors through 'words' and 'pictures', forms the basis of this research investigation. The concept of 'metamorphosing metaphors' within this research inquiry refers to both the linguistic journey the metaphor takes in its chain from scientist to doctor to patient to public, and to the idea of the representation or reworking of such metaphors by visual and artistic means. Research through studio practice, and consequently the artworks that were made alongside the writing of this doctoral thesis, have sought to articulate a discourse between how we *see* and how we *say* disease; what is in essence invisible. This articulation creates opportunities for scientists, clinicians, patients, artists and the wider public to challenge existing preconceptions and to consider new means of conceptualising and verbalising complex scientific concepts.

This research has developed through a collaborative relationship with the TREAT-NMD network and in particular with Professor Volker Straub. Carrying out research in this unique environment has allowed for access to the research and diagnostic laboratories at the Institute of Genetic Medicine and for on-going discussion between myself and Professor Straub regarding the communication of difficult genetic diagnosis, something that Professor Straub does on a day to day basis in his work as a clinician. Carrying out a project in such a collaborative environment has afforded many opportunities to access information and to disseminate the research to a more diverse audience than typically available for fine art practice. This investigation has drawn upon the methods and materials of the artist's studio and the research laboratory and brought these practices together in a synthesis of art and science. As discussed in Chapter 2 of this thesis, the relationship, and the difficulties of the relationship, between art and science is well documented with a clear distinction being made between the culture of the two disciplines (see for example Anker and Nelkin, 2004; Ede, 2000; Fox Keller, 1996; Kemp and Wallace, 2000). This research project negotiates the terrain of these two distinct cultures thus crossing backwards and forwards across disciplinary boundaries through the methods and strategies of arts practice, exhibition and display (Harrison, 2008; Fox Keller, 1996; O'Riordan, 2010).

The relational context of art and science therefore involves an interactive relationship with a number of different people and organisations that can, at times, add pressure particularly in terms of expectation. This reiterates the relationship between art and science that key writers have identified (Anker and Nelkin, 2004; O'Riordan, 2010). Whilst art and science have interacted historically through visualisations of disease and illness, there are still questions arising around the influence of art on science and science on art (O'Riordan, 2010; Wilson, 2010). This research inquiry has afforded an opportunity to explore the possibilities of using artistic concepts and methods to reflect on communication in the biomedical environment represented by TREAT-NMD, especially on the verbal and visual metaphors that people, with different backgrounds and levels of

understanding, often naturally resort to. As this research project argues, when the verbal expression of biomedical concepts becomes highly visual in this way, scientific language starts to share much common ground with the arts, and exploring and building on this natural tendency has formed the basis for the work.

The literature review has shown that the perception of the physical body is a changing landscape in western medicine and culture. Research has identified that the 'visualisation' of disease has undergone a number of significant changes from artistic anatomical drawings through to the present day technical representations of what could be referred to as disease 'data'. It seems evident from current research that with the advent of new technologies and advances in genetic diagnosis, the continued relevance and value of traditional visualisation tools/models such as the medicalised portrait has dissipated. With the ability to access images of what is the essence of ourselves, our DNA, the physical body and therefore the person presenting with the disease has become increasingly absent in the visualisations (Ede, 2005). In contrast, our knowledge of how the physical body works and either stays healthy or becomes diseased, has grown exponentially since the discovery of DNA and the mapping of the human genome. It is apparent that as knowledge is gained about the physical body and disease, the body itself becomes less present thus an alienation from the physical body occurs. As Ede observed:

> The presentation of the corpse in historical collections, whether whole, dissected or in component parts, is more profoundly strange because there lingers a sense of devotional reverence we can no longer share.(Ede, 2005: p.136)

As Chapter 3 argued, the visualisation of Duchenne muscular dystrophy is no longer typified by the medical portraits produced by clinicians such as Duchenne de Boulogne and Heinrich Curschmann. Rather the visualisation of the disease now appears through the technology of the laboratory i.e. the Western blot. This 'absence' of the patient's image is articulated by Gilman who argued that 'the portrait of the sufferer, the portrait of the

patient, is therefore the image of the disease anthropomorphised' (Gilman, 1995); the body is a 'text' to be read.

Whilst the representation of the physical body has 'advanced' along with the technology, i.e. the technical data available is derived from the 'stuff' that physically makes us. This data, is now the site to find out the 'truth' of the body in a literal sense, the metaphorical language used to discuss and explain the complexities of genetics has stayed relatively static. The use of the 'book metaphor' and the 'draft' of the human genome have become embedded in language despite the proposition that this type of language is fundamentally inaccurate relative to how DNA and genetics actually work (Roof, 2007; Nerlich *et al*., 2009). As an element of this research project, the *Language Lab* was employed as a strategic method to engage with the wider audience within the TREAT-NMD network in order to articulate and disseminate the use of metaphorical language. This language, used within a specific network, was collected through the *Language Lab* website and in discussion with Professor Straub, and along with the artworks and studio experiments, these have been displayed in the online gallery thus creating an accessible narrative of the research project. Dissemination of the research in this way has helped to extend and interrogate the research question and to evoke responses from new audiences.

7.2 Practice as research

In a collaborative environment such as the one that existed for this research investigation, the roles within the disciplines are questioned and the artworks interrogated from a different viewpoint than that of the traditional gallery type audience. The quest for 'answers' so often attributed to the sciences can, in this type of environment, be transferred to the artworks, thus the question of 'what does this mean' or 'how is this relevant' arose on a number of occasions during the working relationship. The premise for this investigation has been to draw on expertise from across the art/science disciplines to

consider the representation of the human body and the communication of genetic diagnosis, since the ‘genetic revolution’ ‘in the context of an active medical and scientific environment.

The artworks that interrogate these research ideas have been disseminated through the medium of exhibition and allied research activity to various audiences as part of the research findings. The *Presents as...*exhibition was held in a non-traditional gallery space at the Institute of Genetic Medicine in Newcastle. Whilst complying with the traditional conventions of gallery display i.e. white walls and plinths, the challenge for the exhibition was to reach across the disciplinary boundaries of art and medical science. Images of the *Presents as...*exhibition were projected during an International Conference for Genetic Medicine in Geneva, Switzerland and the research findings were delivered as a paper to the same conference audience. Similarly the *Intersections* exhibition and panel discussion brought together panel members from the arts and the sciences to consider how one discipline may influence the other and to question visual and methodological communication across disciplinary boundaries. Whilst the *Shadowland* work has facilitated new avenues of research allied to the social sciences and the interactions between artist and scientist that culminated in *The Unsolved Case (Der ungelöste Fall)* exhibition.

Attendance at the International Conference in Geneva, and the related activities associated with this conference, allowed for the development of various strategies in order to disseminate the research and to tests the boundaries of the art science relationship in this unique context. The methods employed here are one example of how the research activity of this art science interaction was disseminated to primarily a medical and scientific audience. At the conference the research project and the *Language Lab* website was introduced through the keynote address by Professor Katie Bushby of the TREAT-NMD network (Bushby, 2011) who talked of the project in the context of how varied and wide ranging the work of the TREAT-NMD network is. Subsequently the research paper entitled *Seeing & Saying: Making the invisible visible* (Wilde, 2011) discussed the historic

change that has taken place in the visualisation of Duchenne muscular dystrophy. Drawing on the historic images of Duchenne de Boulogne and Heinrich Curschmann, Chapter 3 highlighted the importance of this to the development of art works made in the studio during the research process. Throughout the conference, images of the *Presents as…*exhibition were projected onto a large screen in the main conference hall and a postcard with images and the question '*How can we see what we cannot say and how can we say what we cannot see*?' (Appendix 6) was distributed to all conference delegates. There was also a traditional style conference poster denoting this research project included in the poster session for this event. (Appendix 4)

These activities brought together the traditional forms of academic research dissemination through a research paper and an academic poster alongside the non-traditional projection of an art exhibition to an audience in a medicalised and scientific environment. Telling the historic story of the disease in this way and in this venue allowed a narrative to emerge from these art works that could shift the perception of ways of *seeing* and *saying* away from those traditionally displayed in this type of medical conference. The artworks therefore took on their own changing narrative, developing a means of communicating more than the *X, Y* or *Z* of the disease, and moved towards the narration of a '*feeling*' about the disease, grounded in the reality of the lives of the patients, researchers and clinicians. This type of dissemination of the research, through strategic methods of display, addresses what can be argued as being the communication mismatch between scientists, healthcare professionals, industry and patient groups, which can result in misperception and unrealistic expectations.

7.3 Conclusions

Throughout this research, exhibitions, conference papers and symposia have rigorously interrogated a number of visual strategies that aim to make visible the invisible processes of the human genome. Alongside this, an engagement with notions of metaphor has allowed the development of visual devices for moving beyond traditional interpretations of the disease. The visual and linguistic narratives that have emerged from the art school, the medical school and the laboratory in the context of collaboration and partnership have culminated here in an arts practice that has been immersed in the world of science. These artworks, whilst emanating from the nexus of the two disciplines also aim to stand alone and be independent from being purely illustrative of, or as a means of communicating difficult genetic diagnosis. Rather, these artworks explore and articulate the story of a disease that is in effect the story that the body is writing.

The critical and highly productive links that have been forged during this PhD research with the Institute of Genetic Medicine, Newcastle and the International Centre for Life, Newcastle are already offering new directions of development with the ESRC Genomics network at Edinburgh University which is producing new research into the methodologies of art /science collaboration. The artworks produced during this research have often taken as their basis the diagnostic tools and visualisations used by clinicians such as Professor Straub in their daily interactions with colleagues and patients. Specifically, due to the current nature of the case, the medical resources used in the making of the *Unsolved Case (Der ungelöste Fall)* work seemed to resonate particularly with Professor Straub as his current research at the time of being involved in the work was very much focused around the use of MRI as a diagnostic tool. The fact of working with such current images and materials brought another aspect to the research that elicited much more of a ‘conversation’ between the artist and scientist as both parties were at a point of immersion in the data: the artist developing new work and the scientist developing a diagnosis.

Using collaborative strategies such as this, it is possible to impact and have an influence on a scientist/clinician. Further exploration, with particular consideration given as to how this ‘influence’ can be measured and evaluated beyond merely collecting ‘conversation’ examples and anecdotal evidence would be a start point for future research. Emergent strands would be to develop strategies and methodologies that consider the impact of an interaction such as this on a clinical practice such as that of Professor Straub. Arts practice and allied interventions are limited to the changes and or influences that they may have on a clinical practice, however as this research has demonstrated, the blurring of boundaries between art and science and therefore communication of difficult concepts can be instrumental in improving our understanding of how we *see* and how we *say* disease.

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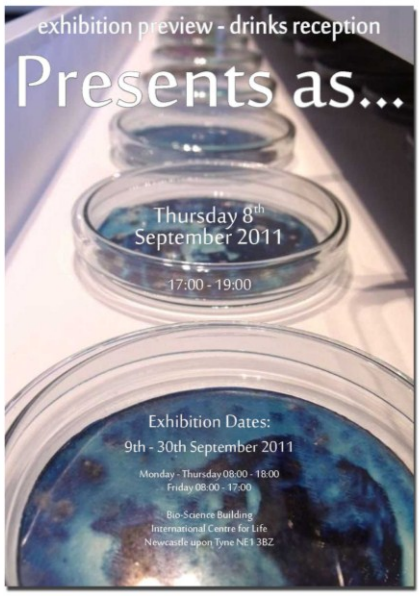
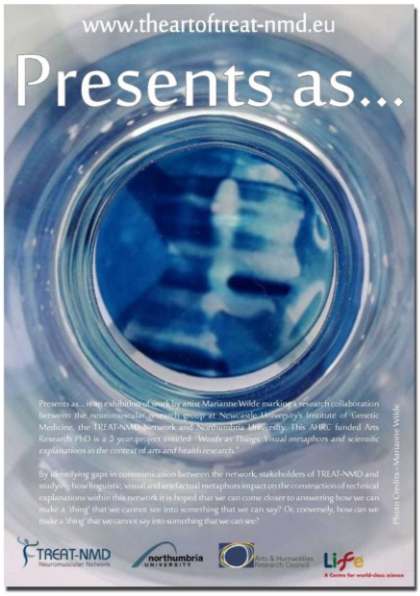
Appendices

Appendix 1A: *Presents as…* exhibition invite





Appendix 1B: *Presents as…* exhibition leaflet

"If your DNA is like a recipe book, a mutation is like a typo that causes you to make the wrong dish."

Presents as... is an exhibition of work by artist Marianne Wilde marking a research collaboration between the neuromuscular research group at Newcastle University's Institute of Genetic Medicine, the TREAT-NMD Network and Northumbria University. This AHRC funded Arts Research PhD is a 3 year project entitled "Words as Things: Visual metaphors and scientific explanations in the context of arts and health research."

By identifying gaps in communication between the network, stakeholders of TREAT-NMD and studying how linguistic, visual and artefactual metaphors impact on the construction of technical explanations within this network it is hoped that we can come closer to answering how we can make a 'thing' that we cannot see into something that we can say? Or, conversely, how can we make a 'thing' that we cannot say into something that we can see?

TREAT-NMD is collaborating on a research project with artist Marianne Wilde that will be looking at the ways in which doctors, patients and scientists communicate both visually and linguistically when explaining the complexity of genetic diseases. The use of linguistic metaphors is commonplace when interpreting the how, what, why and where of DNA and it is these types of metaphor that will form the basis of the investigation.

As TREAT-NMD coodinator Professor Volker Straub explains, "In a highly specialized and complex field like that of inherited muscle diseases, specialists tend to simplify complex facts related to genetic diagnosis, disease mechanisms and potential treatment strategies by using metaphors, analogies and models. Patients and families do the same thing when talking about their conditions. Based on our differing backgrounds we visualize and reflect on things in different ways and Marianne's project is exploring these processes by using art as a more general, non-linguistic concept. Particularly in a multinational, multilingual network like TREAT-NMD, this kind of project has the potential to give us new insights into ways of explaining the diseases we deal with every day."

This exhibition incorporates a body of work that ranges from the exploration of words as physical entities to the aesthetic beauty that can be found in diagnostic laboratory techniques. The work emulates some of the materials used in the laboratory such as gels and combines these with early photographic techniques like the cyanotype, (original Blueprint), photographic process. The work seeks to explore how we both 'see' and 'say' disease and is perhaps exemplified by Presents as, the central piece of the exhibition which combines historic medical portraits from the 1850's with the contemporary images of laboratory diagnostic results (Western Blot) to create a new kind of portraiture.

The use of entomological techniques suggests ideas of collection, identification, and archiving which lead to a body of knowledge, a knowing.

The intention here is to examine the analogies and metaphors in terms of the linguistic, but also, with the use of the historic medical photographs and laboratory techniques to make 'pictures'; not just of what is on the surface, but also what is in essence, the portrait that we all have inside of ourselves encoded in our DNA.

You can follow the project and contribute by adding metaphors at the Language Lab website, which can be found at www.theartoftreat-nmd.eu

Appendix 1C: *Centre for Life* Press Release

Issue date: 23 August '11

Presents as…

Artist premiere's new exhibition "Words as Things: Visual metaphors and scientific explanations in the context of arts and health research" at the Centre for Life.

Artist Marianne Wilde, an AHRC funded Arts Research PhD student/graduate at Northumbria University, unveils a new exhibition, the results, to date, of an ongoing 3 year research collaboration with the neuromuscular research group at The Institute of Genetic Medicine at Newcastle University, the TREAT-NMD Network (www.treat-nmd.eu, an EU-funded network of excellence to advance research and care for people with neuromuscular disease) and Northumbria University.

How often is communication in medicine, for ease, translated through metaphors? The more complex the diagnosis, the more apparent the need becomes to simplify the explanation in order to grasp the significance….

Metaphors are constantly used in explanations of medical concepts – in communications between scientists and doctors, doctors and patients, parents and children, family and friends, children and their peers.

“DNA is a knitting pattern for living things…”

“If your DNA is like a recipe book, a mutation is like a typo that causes you to make the wrong dish.”

Within the genetic diagnosis of particular muscle diseases, Marianne has been looking for possible gaps in this type of communication and by exploring these processes using art works as a more general, non-linguistic concept has begun to ask… *"How can we make a thing that we cannot see into something that we can say? Or conversely, how can we make a 'thing' that we cannot say into something that we can see?"*

This exhibition is the result of observing and talking to scientists working in a laboratory in the presence of ground breaking research and in the diagnosis of patients.

The body of work ranges from the exploration of the words as physical entities to the aesthetic beauty that can be found in diagnostic techniques and is perhaps exemplified by *Presents as*, the central piece of the exhibition which combines historic medical portraits from the 1850's with the contemporary images of laboratory diagnostic results to create a new kind of portraiture.

Marianne's PhD thesis is co-supervised by Volker Straub, professor of neuromuscular genetics at the Institute of Genetic Medicine and coordinator of the international TREAT-NMD network. Interaction with specialists and patients from around the world through TREAT-NMD has reinforced the universality of the concepts that Marianne's work explores, which transcend cultural and linguistic differences.

Marianne's initial research has led to many different discoveries en-route. *"My original intention and thoughts had been to pursue and examine the analogies and metaphors in terms of linguistics, but increasingly with the use of the old photographs and the techniques that I am able to observe in the laboratory, my work has become much more about making 'pictures'; not just about what is on the surface but also what is in essence the portrait that we all have inside of ourselves encoded in our DNA"* she says.

Artist Marianne has already made her mark in the arts world with previous exhibitions in the British Glass Biennale, Stourbridge at the Cambridge Galleries, Cambridge and the Atkinson Gallery in Somerset.

This is a move away from her typical materials of glass and paper and has stretched her imagination and intellectual preconceptions further than she originally thought. "*The influence of the laboratory has been enormous on my*

studio, which in itself feels more like a lab. The materials used are often experimental and not always stable and the gels and cyanotype images degrade over time."

Exhibition: Presents as…. by Marianne Wilde

Dates: Friday 9th September to Friday 30th September 2011

Time: Monday to Thursday 08.00 to 18.00, Friday 08.00 - 17.00

Place: Bio Science Building, Centre for Life, Times Square, Newcastle NE1 3BZ

Press Preview Event: Thursday 8th September 2011. 17.00-19.00

Editors note:

……..For further info visit the project website www.theartoftreat-nmd.eu

……..Artist Marianne Wilde is available for interview

……..Accompanying image: Photo by Marianne Wilde. Image by kind permission of Glasgow University Library Special Collections (Album ***de photographies pathologiques, G B Duchenne 1862).***

For further press information please contact: Vicky Pepys or Nicola McIntosh, Centre for Life Tel; 0191 243 8209 vicky.pepys@life.org.ukm nicola.mcintosh@life.org.uk

www.life.org.uk

www.treat-nmd.eu

Appendix 2: Intersections Event Invite

As part of Newcastle Science Festival Northumbria University and the Centre for Life will be holding an exhibition and panel discussion. The four artists showing in the exhibition are all staff/students at Northumbria University and are working at the intersection of art and science.

Panel members will be -
Professor Christine Borland, Baltic Professor at Northumbria University.
Professor Volker Straub, Institute of Human Genetics, Newcastle University.
Dr Simon Woods, PEALS, Newcastle University.
Ian Simmons, Centre for Life.

The panel discussion will take place on Monday 12th March 7.00 – 8.30 pm at the Centre for Life.

The event is free but please book a ticket online at –
http://www.life.org.uk/whats-on/events/can-art-influence-science-and-does-science-influence-art

Appendix 3: Presentation and Metaphor Collection Jennifer Trust Conference

Welcome to Language Lab

Language Lab is part of a three year AHRC funded PhD research project at Northumbria University by artist Marianne Wilde in collaboration with the TREAT-NMD network. The research is focused around the metaphorical language used by researchers, clinicians and patients when explaining the complexity of genetic diseases. During the project we hope to collect and create an archive of metaphors and analogies that are used across the TREAT-NMD network to describe/explain neuromuscular dystrophies.

We will also be creating new art works for exhibition and metaphors and analogies collected will be placed in a language archive which will available to view from the Language Lab website www.theartoftreat-nmd.eu

"DNA is a knitting pattern for living things..."

"If your DNA is like a recipe book, a mutation is like a typo that causes you to make the wrong dish."

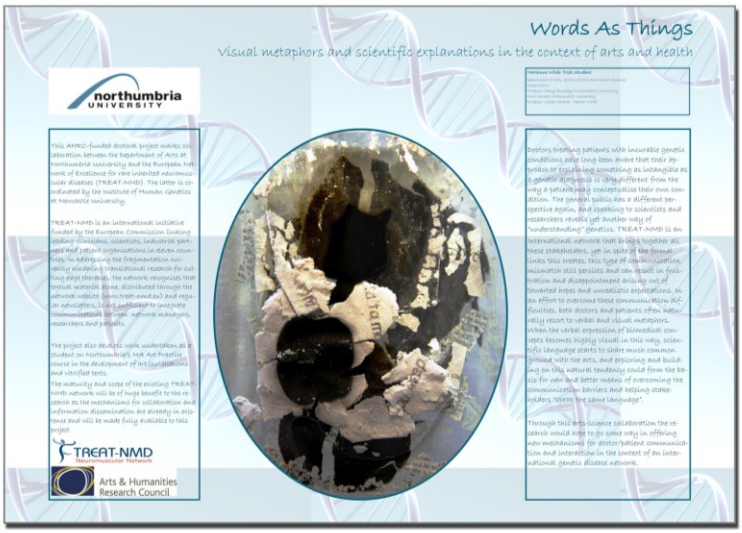
"Imagine you're a computer; the hardware is fine but your software needs some attention."

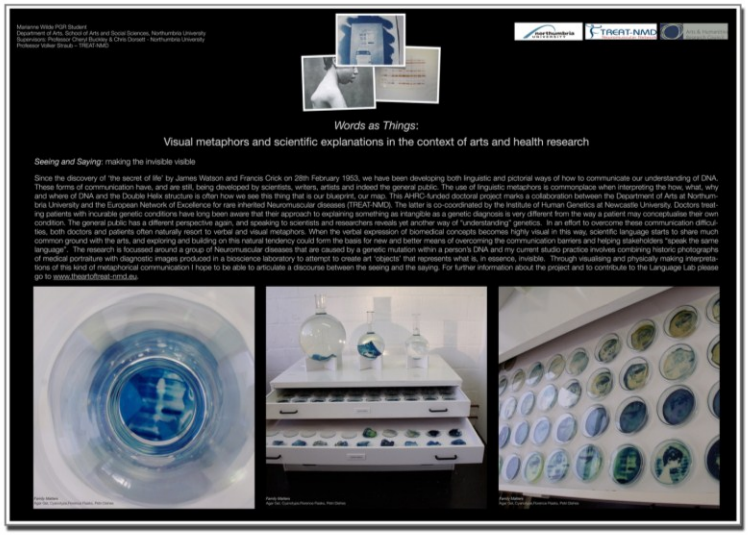
So how do we 'make' these metaphors? Where do they come from? By collecting your metaphors we can begin to look at the kinds of language and the visual images that are being created and then explore what this might begin to tell us about the ways in which we communicate.

Please write your metaphor and/or any comments you may have about the project overleaf and leave at the stand. Alternately please visit the Language Lab website and send your metaphor through the Collection Point page.

Thank you.

Appendix 4: Conference Posters

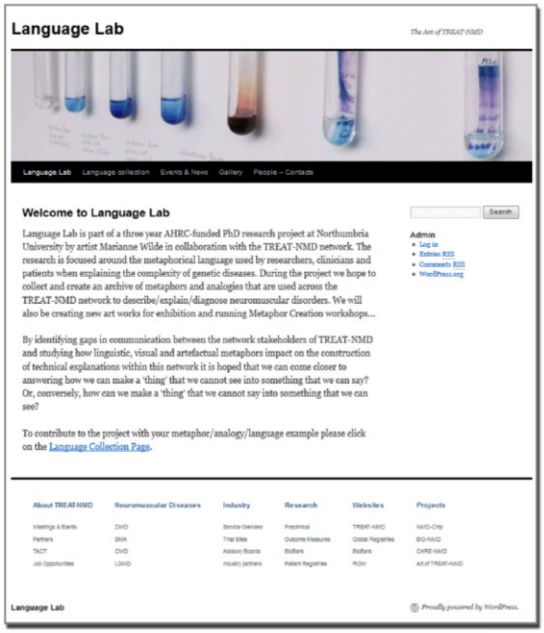


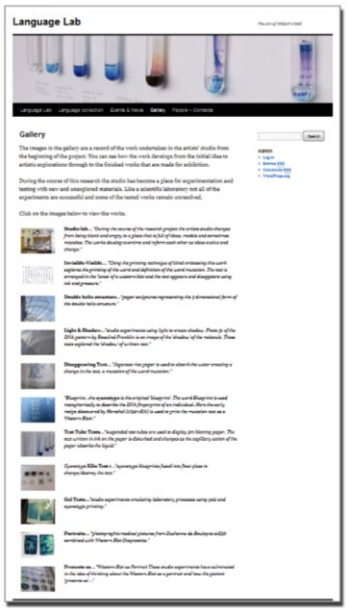



WORDS AS THINGS:
Visual metaphors and scientific explanations in the context of arts and health research
•This AHRC-funded doctoral project marks a collaboration between the Department of Arts at Northumbria University and the European Network of Excellence for rare inherited neuromuscular diseases (TREAT-NMD). The latter is co-ordinated by the Institute of Human Genetics at Newcastle University.
•TREAT-NMD is an international initiative funded by the European Commission linking leading clinicians, scientists, industrial partners and patient organisations in eleven countries. In addressing the fragmentation currently hindering translational research for cutting edge therapies, the network recognises that textual material alone, distributed through the network website (www.treat-nmd.eu) and regular newsletters, is not sufficient to integrate communications between network managers, researchers and patients.
•Doctors treating patients with incurable genetic conditions have long been aware that their approach to explaining something as intangible as a genetic diagnosis is very different from the way a patient may conceptualise their own condition. The general public has a different perspective again, and speaking to scientists and researchers reveals yet another way of "understanding" genetics.
•TREAT-NMD is an International network that brings together all of these stakeholders, yet in spite of the formal links this creates, this type of communication mismatch still persists and can result in frustration and disappointment arising out of thwarted hopes and unrealistic expectations.
•In an effort to overcome these communication difficulties, both doctors and patients often naturally resort to verbal and visual metaphors. When the verbal expression of biomedical concepts becomes highly visual in this way, scientific language starts to share much common ground with the arts, and exploring and building on this natural tendency could form the basis for new and better means of overcoming the communication barriers and helping stakeholders "speak the same language".
•For further information about the project and the Language Lab please go to www.theartoftreat-nmd.eu
TREAT-NMD
Neuromuscular Network
Arts & Humanities Research Council

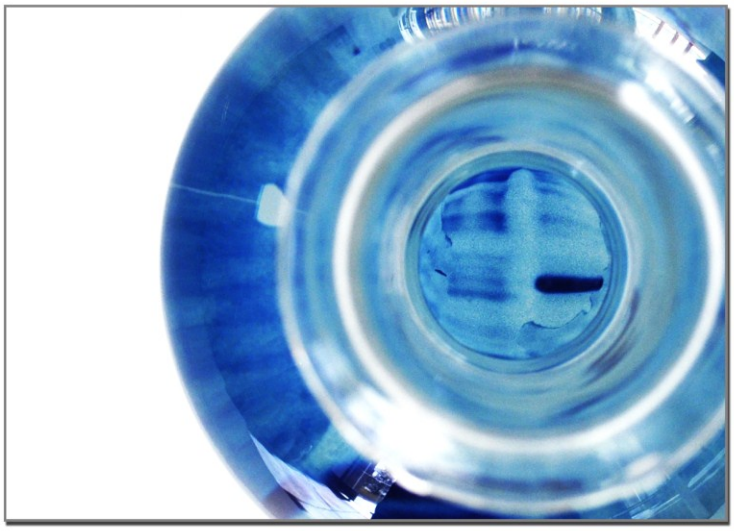

Words as Things:
Visual metaphors and scientific explanations in the context of arts and health research
Seeing and Saying: making the invisible visible
Since the discovery of 'the secret of life' by James Watson and Francis Crick on 28th February 1953, we have been developing both linguistic and pictorial ways of how to communicate our understanding of DNA. These forms of communication have, and are still, being developed by scientists, writers, artists and indeed the general public. The use of linguistic metaphors is commonplace when interpreting the how, what, why and where of DNA and the Double Helix structure is often how we see this thing that is our 'blueprint', our 'map'. This AHRC-funded doctoral project marks a collaboration between the Department of Arts at Northumbria University and the European Network of Excellence for rare inherited Neuromuscular diseases (TREAT-NMD). The latter is co-coordinated by the Institute of Human Genetics at Newcastle University. Doctors treating patients with incurable genetic conditions have long been aware that their approach to explaining something as intangible as a genetic diagnosis is very different from the way a patient may conceptualise their own condition. The general public has a different perspective again, and speaking to scientists and researchers reveals yet another way of "understanding" genetics. In an effort to overcome these communication difficulties, both doctors and patients often naturally resort to verbal and visual metaphors. When the verbal expression of biomedical concepts becomes highly visual in this way, scientific language starts to share much common ground with the arts. The research is focussed around a group of Neuromuscular diseases that are caused by a genetic mutation within a person's DNA and my current studio practice involves combining historic photographs of medical portraiture with diagnostic images produced in a bioscience laboratory to attempt to create art 'objects' that represents what is, in essence, invisible. Through visualising and physically making interpretations of this kind of metaphorical communication I hope to be able to articulate a discourse between the seeing and the saying. For further information about the project and to contribute to the Language Lab please go to www.theartoftreat-nmd.eu .
TREAT-NMD

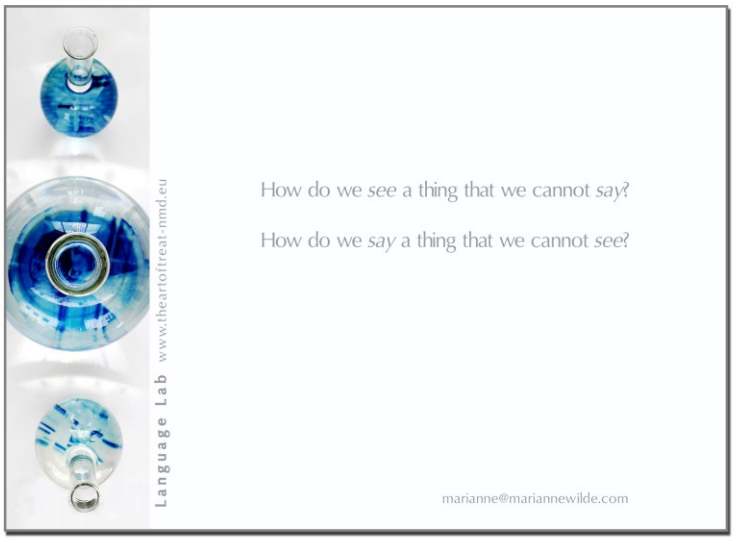
Appendix5: *Language Lab* Website screen shot www.theartoftreat-nmd.eu





Appendix 6: Postcard -TREAT-NMD International Conference, Geneva





Appendix 7: Treat-NMD Newsletter

TREAT-NMD
Neuromuscular Network

4 June 2010
TREAT-N MD newsletter no. 70
view this newsletter online | print newsletter

welcome

update

Welcome to the latest TREAT-NMD newsletter.

This week's edition includes...

- an announcement about a neuromuscular stakeholder meeting with FDA / NIH

- a look at 'The Art of TREAT-NMD', an arts-based research project

- news of a podcast service from the Nationwide Childrens' Hospital in Ohio

- information about the venue alteration for the MDR2010 meeting.

We would like to thank those who have contributed to this week's edition. This newsletter relies on input from our readers. If you have anything you wish to be included in the next newsletter please contact us at info@treat-nmd.eu

at a glance...

12-15 Jun 2010: European Human Genetics Conference :: Gothenburg, Sweden

17-19 Jun 2010: International Conference on Neuromuscular Diseases :: Sao Paulo, Brazil

19-23 Jun 2010 20th Meeting of the European Neurological Society :: Berlin, Germany

24-27 Jun 2010 Parent Project Muscular Dystrophy Annual Conference :: Denver, Colorado, USA

24-27 Jun 2010 Families of SMA Annual Conference :: Santa Clara, California, USA

TBC 16 Jul 2010 MDR2010 :: Padova, Italy

18-23 Jul 2010: 12th International Congress on Neuromuscular Diseases :: Naples, Italy

Neuromuscular stakeholders to meet with FDA and NIH on AON therapies in September

We are pleased to announce the upcoming FDA and NIH co-sponsored meeting Med Antisense Oligonucleotide (AON) Therapies: Regulatory Science and Stakeholder Input, to be held on the 27th and 28th September, 2010 in Washington DC, USA.

Given the growing number of AONs entering clinical development for multiple different neuromuscular disorders, TREAT-NMD, in collaboration with the FDA and patient advocacy communities, are taking a proactive role in developing and promoting regulatory science for the AONs by providing a forum for neuromuscular disease stakeholders to present the 'state-of-the-science' and exchange information on issues relevant to the AONs.

The meeting will focus on four sessions:

- Toxicology and Preclinical Findings to Date
- Biomarkers
- Clinical Trial Outcomes
  Patient Registries and Assessing Long-Term Outcomes

and will be concerned with four neuromuscular disorders:

- Amyotrophic Lateral Sclerosis
- Duchenne Muscular Dystrophy
- Myotonic Dystrophy
- Spinal Muscular Atrophy

The goal of this meeting is to allow stakeholders to explore potential pathways forward for the AONs with the eventual goal of creating a sound scientific anchoring for neuromuscular disease clinical development programs. These initial discussions should be seen as first steps in what is likely to be an iterative process intended to lay the ground work for future collaborations.

Over 120 stakeholders will be invited to participate in the meeting, consisting of researchers, academics, industry and patient group representatives. In order to accommodate all those unable to attend the meeting due to space limitations or geographical distance, the whole meeting will be streamed on the web via a dedicated weblink (to be made available shortly).

Additional details will follow in due course. In the meantime, if you have any specific queries please contact Abby Sirmons or Emma Hyslop.

The Steering Committee Chairs

Kate Bushby, Newcastle, TREAT-NMD
Ed Connor, CMMC
Elizabeth McNeil, FDA
John Porter, NIH

MORE >

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Network Meeting: Las Vegas, Nevada, USA

29 Aug - 1 Sep European Meeting on Next Generation Sequencing :: Leiden, Netherlands

9-10 Sept 2010 MD2010 - 4th conference for the Muscular Dystrophy Association of Western Australia :: Perth, Western Australia

18 Sept 2010: Muscular Dystrophy Campaign Conference :: Birmingham, UK

20-22 Sept 2010 Muscle Study Group Annual Meeting :: Buffalo, NY, USA

4-5 Oct 2010: 7th UK SMA Researchers Conference :: Llanwddyn, Wales, UK

12-16 Oct 2010: World Muscle Society International Congress :: Kumamoto, Japan

12-13 Nov 2010 Action Duchenne 6th Annual Conference :: London, UK

16 Nov 2010 European Conference :: Manchester UK

Please note: This is only a selection of upcoming meetings. To see all our listed meetings click here.

Language Lab: rethinking medical communication through art and metaphor

"If your DNA is like a recipe book, a mutation is like a typo that causes you to make the wrong dish."

"Imagine you're a computer, the hardware is fine but your software needs some attention."

TREAT-NMD is collaborating on a research project with artist Marianne Ploeger to explore the ways in which doctors, patients and scientists communicate both visually and linguistically when explaining the complexity of genetic diseases. The use of linguistic metaphors is commonplace when interpreting the how, what, why and where of DNA and it is these types of metaphor that will form the basis of this investigation.

As TREAT-NMD coordinator Professor Volker Straub explains, "In a highly specialized and complex field like that of inherited muscle diseases, specialists tend to simplify complex facts related to genetic diagnosis, disease mechanisms and potential treatment strategies by using metaphors, analogies and models. Patients and families do the same thing when talking about their conditions. Based on our differing backgrounds we visualize and reflect on things in different ways and Marianne's project is going to investigate exactly how we do that and what we can learn from it. As part of a truly multinational, multilingual network like TREAT-NMD, this kind of project has the potential to give us new insights into ways of explaining the diseases we deal with every day."

Communications of this type are often referred to as scientific metaphors and are used generally when explaining complex concepts currently. Examples are 'the factory' or 'the blueprint'. These terms are often widely debated and are constantly being developed by researchers, writers, artists and indeed the general public.

This three year, AHRC funded research project is being carried out by Marianne at Northumbria University and is entitled Words as things: visual metaphors and scientific explanations in the context of arts and health research. Over the course of the project the metaphorical language used within the network will be collected, interpreted into visual art forms and an archive created.

By identifying gaps in communication between the network stakeholders of TREAT-NMD and studying how linguistic, visual and artefactual metaphors impact on the construction of technical explanations within this network it is hoped that we can come closer to answering how we can make a 'thing' that we cannot see into something that we can see? Or, conversely, how can we make a 'thing' that we cannot see into something that we can see?

You can follow the project and contribute by adding metaphors at the Language Lab website, which can be found at www.theartofthedna.org.au

MORE >

US children's hospital offers podcasts focusing on neuromuscular disorders

Scientists and clinicians at the Nationwide Children's Hospital in Columbus, Ohio have launched a monthly podcast entitled, "This Month in Muscular Dystrophy," featuring internationally known scientists discussing the latest research in muscular dystrophy and other neuromuscular disorders.

The programs are posted each month at www.NationwideChildrens.org/musculardystrophy.

The podcasts are geared toward patients, their families and primary care physicians who take care of patients with neuromuscular diseases.

Hosted by Kevin Flanigan, MD, an attending physician in Neurology at Nationwide Children's Hospital and a principal investigator in the Center for Gene Therapy in The Research Institute at Nationwide Children's, the programs include interviews with authors of recent scientific publications discussing the latest research and provides understanding of inherited neuromuscular diseases and what their findings might mean for treatment.

The initial programs include:

Jerry Mendell, MD, director of the Center for Gene Therapy in The Research Institute at Nationwide Children's Hospital and professor of Pediatrics and Pathology at The Ohio State University College of Medicine, discusses gene transfer of follistatin and the implications for sickle disease.

Iain Keague, PhD, an investigator in the Center for Gene Therapy in The Research Institute at Nationwide Children's and assistant professor of Pediatrics at Ohio State, explains sibling rare results in animal models of gene transfer in spinal muscular atrophy.

Kate Bushby, MSCN8, MD, professor of Neuromuscular Genetics at Newcastle University, PI, discusses the recent publication of care standards in Duchenne muscular dystrophy (DMD). These standards address the diagnosis and management of DMD, including pharmacological and non-pharmacological therapies. Dr. Bushby is also the coordinator of TREAT-NMD (Translational Research in Europe – Assessment and Treatment of Neuromuscular Diseases), a European network focusing on bringing advances in neuromuscular disease treatment rapidly and effectively to patients.

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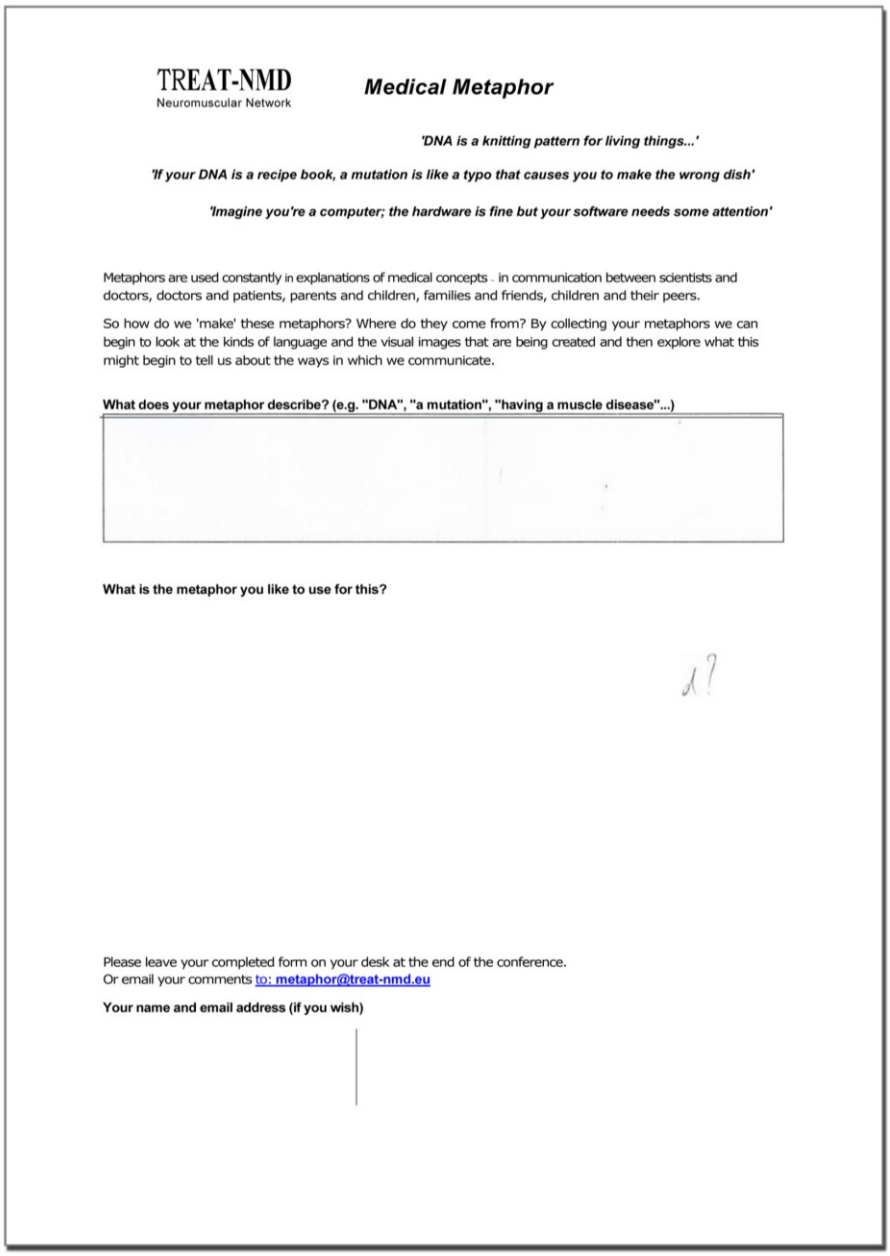
Appendix 8: Metaphor Collection Form -TREAT-NMD Conference, Brussels



TREAT-NMD
Neuromuscular Network

Medical Metaphor

'DNA is a knitting pattern for living things...'

'If your DNA is a recipe book, a mutation is like a typo that causes you to make the wrong dish'

'Imagine you're a computer; the hardware is fine but your software needs some attention'

Metaphors are used constantly in explanations of medical concepts - in communication between scientists and doctors, doctors and patients, parents and children, families and friends, children and their peers.

So how do we 'make' these metaphors? Where do they come from? By collecting your metaphors we can begin to look at the kinds of language and the visual images that are being created and then explore what this might begin to tell us about the ways in which we communicate.

What does your metaphor describe? (e.g. "DNA", "a mutation", "having a muscle disease"...)

What is the metaphor you like to use for this?

Please leave your completed form on your desk at the end of the conference.
Or email your comments to: **metaphor@treat-nmd.eu**

Your name and email address (if you wish)

What does your metaphor describe? E.g. DNA - a mutation - having a muscle disease

What is the metaphor you like or have heard used for this?

If you wish to leave your email address to be updated about the project please do so here. Your details will not be used for any other purpose or shared with any third party.

Appendix 9: Collected metaphors

Description	Metaphor/Analogy/Simile	Contributor
Carrier testing that is not 100%	Imagine a gene as a zipper with a million teeth. There could be a missing tooth, a crooked tooth, an extra tooth at any point in that zipper that would cause it not to work. We only test for the 97 most common changes in the zipper because we can't look at all one million teeth of the zipper.	dlafayette@gmail.com
Chromosomes	They are like the instruction manual on how to build a human body and keep it running normally. If there are extra or missing chromosomes, it's like the body got the wrong instruction manual.	dlafayette@tuftsmedicalcenter.org
nondisjunction	It's like you're dividing up jelly beans - one for me, one for you, and you make a mistake.	apache@treatnmd.ncl.ac.uk
Chromosomes	Chromosomes are just packages which organize genes, which are the instructions that tell our cells how to grow, develop, and live.	apache@treatnmd.ncl.ac.uk
Chromosomes and genes	Spices that are used in a recipe -- this was used for a person from Africa who had no English and also no concept of genetics and inheritance at all, but had the idea that spices are very powerful and influential over many things in life. The wrong spice or too much spice was used to explain mutations and extra chromosomes.	apache@treatnmd.ncl.ac.uk
The difference between chromosomes/karyotyping and genes/sequencing	A karyotype is like taking a picture of a city's skyline...the genes are the offices inside each building...the equipment in the offices would be the bases. You cant see the office structure from an airplane (doing a karyotype) but if you go inside and look at the desks/chairs/etc, you can see the building in greater detail (genetic testing/sequencing)	ana_morales_reyes@yahoo.com

Mutated gene	Non-working gene; changed gene; non-typical gene	apache@treatnmd.ncl.ac.uk
Mutation	A change in a gene; a typo; a misspelling. Can be like a chapter or a page missing in a book, or just one or a few letters wrong.	apache@treatnmd.ncl.ac.uk
Normal (wildtype) gene	Typical gene; working gene	apache@treatnmd.ncl.ac.uk
Association between chromosomes and genes	Chromosomes are like looking at the spine of a book. When we look at a child's (foetus') chromosomes it's like making sure all the books in the series are here. Genes are paragraphs in the book. Just by looking at the spine of the book, we can't tell if there is a typo on page 56. If we want to look for a typo (genetic disease) we have to know about what book and what page else we're likely never to find it.	Kristin.Baldwin@genzyme.com
Chromosome aneuplodies	The chromosomes are like a recipe for the body. Having an extra chromosome is like adding too much of certain ingredients into your recipe - You're going to change your outcome.	Kristin.Baldwin@genzyme.com
Being a carrier for a condition	You have two copies of this instruction. One copy has a typo that makes the instruction unusable. But the other instruction is fine, and so you don't have a problem.	Kristin.Baldwin@genzyme.com
the difference between genes and chromosomes and how we test for changes in each	Your genetic information is like an encyclopaedia. Each chromosome is like a volume of the encyclopaedia. Genes the topics within each volume. It is easy to see if a volume/chromosome is extra or missing just by taking a quick look at the set. However, this will not tell us if the genes are normal. In order to find changes within genes we must know which volume to look in and how the topics are arranged. It is easier to find those changes if they have been seen before and so we know on which page to look or even in which sentence the change is located.	apache@treatnmd.ncl.ac.uk
osteogenesis imperfecta	If you think of your bones like bricks used to build a house - one severe type of OI is	hugginsm@hhsc.ca

(brittle bone disease)	like having the bricks made out of foam or sponge, another type of OI is like having the bricks made normally but the mortar is either missing or not strong enough to hold the bricks together.	
This metaphor describes the reduced movement I have in my right hand and arm.	It is like someone has put a screw top on the bottle wrongly and it isn't interacting with the thread around the bottle top like it should so my hand and arm do not turn / function properly.	toni.abram1@btopenworld.com
This metaphor describes the pains I feel in my left thigh.	Sometimes: Like someone is stabbing my thigh with a knitting needle. On waking in the night on occasion: Like my thigh is being ripped apart - terrifying.	toni.abram1@btopenworld.com
My metaphor describes the centronuclear myopathies of which there are three different forms of the condition, namely x-linked myotubular myopathy, autosomal dominant centronuclear myopathy and autosomal recessive centronuclear myopathy.	An umbrella term: The centronuclear myopathies is an umbrella term which encompasses the three different forms of the condition, named above. An illustration showing how this works can be found at http://centronuclear.org.uk/theinformationpoint2010/pages/about/about.html Together with information about the three forms of the condition.	toni.abram1@btopenworld.com
treatment	Treating MD right now is like working on plumbing. The drain is clogged, and at this time, all scientists can do is pour nuts and bolts down the drain. They know where the problem is, and how to get close, but cannot get more specific at this time.	Patrick Moeschen New Hampshire USA
DNA	Like a 'zipper' – can be zipped and unzipped (base pairs like the teeth of the zipper).	Anon

EXons, introns and exon skipping	Imagined you have programmed your VCR to record a movie on TV: problem, there are a lot of ads (INTRONS). Your VCR is very clever and can stop recording at ad times so you can see the whole movie. Sometimes your VCR fails and forgets to tape a couple of the movie bits between ads (EXONS), if what is missing is not important (a silly car chase) it may not be relevant (Becker), if it is the scebne where the evil guy is unmasked the rest of the movie may not make any sense (DMD). When Exon Skipping we deliberately delete a couple of the scenes (getting rid perhaps of a secondary character) to make a shorter movie but an understandable one...	Virginia Arechavala-Gomeze